

UK National Screening Committee (UK NSC)

Screening for prostate cancer

Consultation responses from members of the public

Date: 11 May 2026

Note: Some personally identifiable information in this document has been redacted; redacted text is indicated by *****.

#	Consultation response
P1	Affected Comment: I lost my father to prostate cancer and therefore would I imagine that I am at significant risk. Evidence Comment: Yes, I find the argument that the UK cannot be compared with Sweden (where a successful programme operates) absolutely ridiculous. Apparently, the population there is 'too different'... which I read as code for fewer minority ethnic groups. There is an irony in that conclusion. The very groups that make England different are the groups at higher risk... black men who have roughly double the incidence and double the mortality. I also disagree with the Committee's argument that prostate cancer screening risks 'overdiagnosis' and 'overtreatment.' This assessment is stuck in the PSA tests of the 1990s... too many false positives, too many biopsies, too many harms caused in the quest to avoid harm. That world has gone. Modern risk-based approaches... don't biopsy everyone with a raised PSA... they're MRI'd, risk-stratified and the majority left alone. Discussion comment: I am very concerned at the make up of the panel given the disproportionate impact that the condition has upon black men (of whom there appear to have been none on the panel, as well as 8 women out of a panel of 11). I question whether a similar conclusion would have been reached for a condition which disproportionately affected white people. Recommendation comment: Yes, it will save lives like those of my father. Alternatives comment: A start would be for the government to take the condition seriously and on a par with other cancers.

	Other comments: This decision is not only wrong, it is offensive.
P2	Affected Comment: Father has prostate cancer so my risk is higher. Evidence Comment: Review committee not representative of UK population at risk of this disease. Screening already in place in other countries and evidence clear that positive benefit. Over treatment risks overstated and based on process of high Psa always leading to biopsy. Risk based pathway with MRI screening negates this argument. Discussion comment: Recommendations wrong. Argument that Sweden not representative of UK ignores the fact that they have a lower proportion of high risk groups (men of colour) so benefits here would be even greater! Madness. Recommendation comment: Yes absolutely. Alternative is diagnosis by chance when normally too late. Bottom line screening would cost now and save money and lives later so politicians will not support a process that will not benefit them now. Shame on committee. Alternatives comment: Screening already shown to work – makes no sense to look at untested alternatives. Sadly I believe this decision would not have been made if the condition only affected women..... Other comments: Screen!

P3	Affected Comment: Yes, Father-in -Law and uncles Discussion comment: There is no medical intervention that is without some impact – however, the lack of intervention is often a lot worse. This is a killer and men are dying that could be saved if found sooner. I think this is a risk that many men are willing to take. The numbers are so high, we need to act. Recommendation comment: Yes, the numbers are high and early detection works.
P4	Affected Comment: I cannot believe we are living in the dark ages! I am personally very worried as I was adopted & do not know the medical history of my birth father. This could include prostate cancer. I am 59 years of age & have a PSA test. I have friends who have died from prostate cancer & the PSA is the best non invasive method currently to pick up early signs. It means I have to proactively ask for a PSA test yearly which may end up saving my life. Evidence Comment: Clinical practice has changed. Nowadays I would expect an accurate MRI scan if signs/ symptoms or high PSA result. I believe the outcome is disgraceful & discrimination against men in general, especially black men who have double the risk. Yes the specificity of the PSA could improve and it is currently the best option. Why do we not have prostate clinics? Why has the pathway not changed in years? Why is it still a roulette wheel approach so that a man dies every 45 minutes? Discussion comment: Pathways need updating & screen high risk groups immediately with PSA test Recommendation comment: No reason whatsoever Alternatives comment: Improve pathways, patient education, increase MRI capacity or use drop in clinical late at night, encourage men to seek early diagnosis, work with Prostate Cancer UK, use drugs earlier, recognise changes in clinical practice, recognise very unlikely to over treat in UK (we normally under treat cf US for example)

Affected Comment:

Prostate cancer has affected someone very close to me – a friend – and his experience strongly demonstrates the consequences of not having targeted screening.

He was diagnosed with prostate cancer only by chance, not because he had symptoms and not because he was flagged as high risk. At no point had he been advised that a family history of prostate cancer placed him at higher risk, even though a close relative of his had previously died from metastatic prostate cancer. Looking back, it is very clear that a risk-based screening programme would have identified his cancer much earlier.

He also shared the impact of late diagnosis on men he met during treatment and recovery – individuals whose cancers were caught at an advanced stage. For them and their families, the physical, emotional and financial toll was severe. Many of them also had recognised risk factors, such as being Black or having a family history of prostate cancer, yet they had never been offered targeted testing.

The common thread in what he observed – and what has affected those around him – is that early detection is largely a matter of luck rather than a structured NHS pathway. Men with clear risk factors are not being proactively identified or invited for testing, and many only receive a diagnosis once treatment is complex, prolonged and often palliative rather than curative.

This has influenced not only him but everyone who cares about him. It has highlighted how preventable many cases of late-stage prostate cancer could be if screening were directed at those most at risk.

Evidence Comment:

Yes. The most significant issue is that the evidence base used appears to rely heavily on studies from the PSA era of the 1990s, when biopsies were routinely triggered by a raised PSA. The harms associated with that older model – overdiagnosis, overtreatment and biopsy-related complications – are well documented, but they no longer reflect current practice.

Key modern evidence appears to have been under-emphasised or excluded, particularly:

Risk-stratified screening approaches used in Sweden, Norway, and regions of Germany.

Evidence showing that raised PSA can now be followed with MRI rather than automatic biopsy.

Studies demonstrating that targeted screening detects more clinically significant cancer while reducing unnecessary procedures.

The omission or down-weighting of these data risks basing policy on outdated assumptions rather than contemporary outcomes.

There also appears to be limited consideration of outcomes by ethnicity. Black men, who have roughly double the incidence and double the mortality, cannot reasonably be evaluated using population-average data that do not reflect their risk profile.

Discussion comment:

The recommendation to reject targeted screening does not seem to align with the emerging international consensus or with the modern risk-stratified clinical pathway.

The conclusion that screening still poses significant risks of overdiagnosis and overtreatment appears to extrapolate from an historical model of PSA-triggered biopsy rather than present-day practice. The logic is circular: screening is deemed too harmful based on a method that is no longer proposed.

The review also appears to apply Sweden's learnings selectively – discounting their positive results because the population is "different". However, England's population is different in a way that should strengthen, not weaken, the case for targeted screening: Black men and those with a family history are at significantly higher risk. If screening is justified in a lower-risk population, it is difficult to justify refusing it for a higher-risk population.

Recommendation comment:

Yes – screening should be recommended, specifically in a targeted, risk-stratified form.

A modern screening model should not biopsy every man with a raised PSA. Instead, it must follow the pathway already used successfully abroad: PSA → MRI → risk-stratified management. This approach reduces unnecessary invasive investigations while increasing the early detection of clinically significant cancer.

Targeted screening for high-risk groups (Black men and men with family history) would prevent many late-stage diagnoses. Even a modest reduction in late-stage presentations would save lives and significantly reduce the financial and capacity pressures on oncology services.

Screening saves lives. The decision currently turns too much on short-term cost avoidance rather than long-term clinical and economic benefit.

Alternatives comment:

Alternative or complementary measures that would reduce preventable deaths include:

Automatic clinical prompts for GPs when a patient reports a family history of prostate cancer.

Clear guidance encouraging PSA testing for Black men and those with family history, rather than leaving this to individual initiative.

Public education campaigns focused on high-risk groups, similar to those used for breast cancer awareness.

Improved recording of ethnicity and family history in medical records to support risk recognition.

Standardised post-PSA pathways (PSA → MRI) to avoid unnecessary biopsies and ensure consistent care.

These measures would not replace screening, but they would provide meaningful interim benefit.

Other comments:

recommend that the UK NSC re-run its evaluation using:

Evidence from risk-based screening, not historical PSA-biopsy studies.

	Outcomes broken down by ethnicity and family history, not population-aggregate figures that mask high-risk subgroups. Health-economic modelling that considers the avoided costs of late-stage disease, not only short-term spending. If needed, the Committee could initially pilot targeted screening in a limited number of ICS regions with large high-risk populations. This would produce UK-specific data without delaying life-saving policy indefinitely. Lives are being lost unnecessarily. The technology, research evidence and international frameworks for safe risk-based screening already exist. The UK now needs the policy decision that enables their use.
P6	Affected Comment: It has severely affected someone I know, who found out they had prostate cancer by accident. Screening saves lives and money and should be introduced without delay Evidence Comment: Positive Evidence from other countries was dismissed. Why was this? Discussion comment: I fundamentally disagree with the findings. Screening must be initiated without delay Recommendation comment: Should be recommended. Alternatives comment: Screening Other comments: Was the Chair of the committee independent of any treasury influence? Do they hold any other government position?
P7	Affected Comment: Yes I have three close friends who have prostate cancer. All three found out by good fortune during tests for other issues. Only one had a familial history but had no idea about PSA testing. Men are dying unnecessarily due to a lack of a proper national strategy and targeted screening programme.

I fundamntally disagree with the proposed course of action to not implement a targeted prostate screening programme as there is sufficient eveidence already exisitng to demonstrate that we can identify those men at highest risk and we can alert them to the risks and include them in an early detection proframme which will save the NHS and their families money and distress of avoidable premature mortality.

This is a poor short term decision driven by short term expenditure avoidance and is the wrong policy to adopt – we can and must do better as a Country.

Evidence Comment:

Yes there is no population based cost benefit analysis based on the identified high risk population – the current analysis is based on the whole/ broad population and loses the identifieable beneift of a strategy targeted at the high risk population as a proper cost benefit analysis of cost Vs live saved and avoided costs of last year of life costs vs reduction in prostate cancer spend with early detection.

This has not been done.

Discussion comment:

Yes The analysis of costs and benfits needs to be around the identified high risk population (which is growing with an ageing population) and the benefits of early detection and prevention of premature mortality.

The national policy needs to be more focused on ways to save lives in the high risk population and this will give a different conclusion.

Recommendation comment:

Screening should be recommended for the high risk population – it is morally idefensible not to do this and a waste of tax payers money as we will be paying more per life lost than per life saved for this group of men.

Alternatives comment:

The best policy is early detection and treatment when we know we have the tools to do this but targeted at the high risk popualtion not the whole population.

The governement is making the same mistake as the winter fuel issue – not thinking the issue through from a more targeted approach – those who will benefit the most are those most at risk / the poorest communities.

Other comments:

Yes stop faffing around and get on with it.

P8	Affected Comment: Yes, this condition has affected several friends – some have been lucky because the condition was picked up through other investigations. Some have been unlucky in that they were diagnosed late; too late for early effective treatments. It is bordering on criminal when a man – with, (or without) demographic risk factors of ethnicity of family history, who are well informed are blocked from receiving a test by their GP because they are ‘overthinking things’. Evidence Comment: The evidence emerging from other countries about targeted approaches should have more weight to the decisions made in this country. Discussion comment: Very disappointed that the ‘professional’ committee took the decision to not recommend a targeted screening programme – when professional clinical bodies – such as Royal Colleges supported it. The Government’s ‘Fit for the Future’; 10 year health plan talks about the 3 left shifts and prevention being one of them. This is a very tangible way of demonstrating commitment to prevention. Recommendation comment: Targeted, algorithm driven, assisted by AI should be implemented, like we did for CVD prevention and the prescribing of statins for people with a risk score >20%. Alternatives comment: A public health campaign, widely promotion of risk factors to the public and making access to initial testing easy and not a battle through primary care. Other comments: Think again – Mr Streeting!

P9	Affected Comment: I'm a prostate cancer survivor the screening outlined in this review is biased by the financial objectives of an administration that has ignored the human costs of a large group of men that have made a significant contribution to the country and has now turned their backs on them. Think again please ? Evidence Comment: What about black and ethnic men's risk ? Discussion comment: As a retired ***** think men please. Recommendation comment: I was lucky diagnosed with no symptoms. We don't need luck we need a fully funded functional system to detect and avoid long term care and pain. Alternatives comment: Low cost self PAS testing for men over 50 years. Other comments: Please think again.

P10	Affected Comment: I know of several men who have had this condition, so yes, it has affected me in the broadest sense. Evidence Comment: Missed perhaps not -valued, most definitely not – as if it were, the decision would have been the opposite. Discussion comment: The conclusion is wrong. the so year 10-year plan is supposed to be looking to prevention. screening is a major tool in the armoury of prevention. look again. change the outcome. consult with those communities most at risk, and get the answer right. screening saves lives. Recommendation comment: SHOULD BE RECOMMENDED – because (i) it saves lives, (ii) it impacts the vulnerable and black and ethnic communities (iii) long term it saves money too, cheaper to invest in early diagnoses, than late treatment. Alternatives comment: there are. but that doesnt mean the alternatives (i) work or (ii) are cost effective. Other comments: SCREEN – start the process NOW, get it done.
P11	Affected Comment: I have had many colleagues and friends over the years who have had Prostate cancer – some have had good outcomes and some have not Recommendation comment: There should be a screening programme for Prostate cancer for all men over a certain age – the lower the age the better Alternatives comment: Please, just implement a screening programme Other comments: A case needs to be made to fund a national screening programme. If it is deemed unworkable due to affordability, then perhaps a programme should be set up under value based healthcare principles to truly explore the costs of not implementing a screening programme.

	Screening, as well as vaccination / increasing exercise / healthy eating, all fit in with keeping people out of the acute sector..... surely a no-brainer??
P12	Affected Comment: My husband has prostate cancer, and when nursing I nursed patients with end-stage prostate cancer Evidence Comment: I would like to know what the false positive rate of mammograms is, as a comparative – bearing in mind that mammograms are a much more expensive and invasive test (in terms of requiring special machinery, radiographers, and changing facilities, and people to undress, and go through an uncomfortable procedure) Discussion comment: A PSA test is relatively cheap, non-invasive (except that it requires taking blood, but this is so routine as to be virtually non-invasive). Currently it requires the person to have symptoms, which may be relatively late stage and therefore presentation is often late stage, and requires the GP to connect the symptoms to the test – my husband had repeated UTI's before getting a PSA test – and was then referred to an MRI before treatment. I'm mesmerised by the statement that MRI's are not conclusive – maybe not but can be used for 'watch and wait'. Now there is a really effective diagnostic and treatment protocol (not there when I first started nursing) it seems criminal not to use it. And the cost of late stage treatment and a horrible death seem unacceptable for a condition that's common and successfully treatable these days, and where the initial diagnostic (PSA) is really cheap and easy. Recommendation comment: Absolutely should happen. It's relatively cheap, easy and the protocol once diagnosis is confirmed, leads to treatment that is pretty effective. This could and should be done by GP's keeping the costs down (in comparison to breast cancer). I think given the rising age and demographic, and the fact that it disproportionately affects black men, this is a no-brainer. Alternatives comment: I'm not sure what these are – if you mean a public appeal to people to go and be regularly checked, then it's obvious that this will miss a substantial number of men to whom this possibility never occurs. A large majority of my friends have had diagnosis and successful treatment (all white Social Class 1) none of whom thought it could happen to them, until it did. We should make sure all men have a routine regular PSA which is then followed up by non-invasive MRI if necessary.

	Other comments: no – keep it simple – do a PSA screening programme to follow-up with a full diagnostic protocol as necessary – do the math!
P13	Affected Comment: I lost my father and a brother to prostate cancer. My brother showed no symptoms until it had spread to his bones and was terminal. Screening him because of his father's death would have saved his life. I have 2 sons. I desperately want them to be regularly screened Evidence Comment: Black men and men with a family history of prostate cancer has a much bigger risk, Screening with MRI could save thousands of lives False positives and over treatment could easily be avoided by follow up M R I scans after a positive blood test Discussion comment: Screening and non invasive targeted MRI scans for relatives of men with a history of prostate cancer would save lives. Prostate cancer is the most common cancer for men in the UK. We screen for breast, cervical and bowel cancer yet not prostate. Why? I suspect it's money and that is cruel and immoral. Recommendation comment: Screening and non invasive targeted MRI scans for relatives of men with a history of prostate cancer would save lives. Prostate cancer is the most common cancer for men in the UK. We screen for breast, cervical and bowel cancer yet not prostate. Why? I suspect it's money and that is cruel and immoral. Alternatives comment: Screen all men for genetic markers Screen all men with a family history Screen all men of Afro Caribbean descent Then Screen all Use targeted M R I scans before starting treatment Other comments:

	The cost of targeted screening will be less than the cost of treatment of thousands of men. The technology of MRI targeted scans should identify the most aggressive cancers and prevent unnecessary treatment.
P14	Affected Comment: My paternal uncle died of metastasized prostate cancer in *****. He had no symptoms and it was picked up as part of a routine 'well man' GP appointment. Since then my Dad has requested regular PSA tests from his GP. I was a cancer services manager in the NHS *****. I saw how quickly we can diagnose prostate cancer and decide, with the patient, whether treatment is required or whether it's more appropriate to 'actively monitor' the situation. We have enough technology nowadays to differentiate between the patients who need treatment and those who don't. A screening programme will cost more upfront but will save lives (and therefore money) in the longer term especially for high risk populations such as black men. A screening programme should be implemented as soon as possible. Recommendation comment: A screening programme will cost more upfront but will save lives (and therefore money) in the longer term especially for high risk populations such as black men. A screening programme should be implemented as soon as possible.
P15	Affected Comment: Please don't underestimate the worry surround this forest. All men of a certain age worry about this. We all know someone who has had prostate cancer and we worry. There are many conversations, many trips to GPs that could be saved. Recommendation comment: Should – see above

P16	Affected Comment: My father had prostate cancer, caught late, a radical prostatectomy, his remaining life worrying, and I wouldn't wish that on any one. Recommendation comment: Screening should absolutely be recommended. The government mantra has been from sickness to prevention – how can this leading cause of cancer not be screened for – madness. With a greater prevalence in black men the step to withdraw screening can only widen the inequalities gap – do better. Alternatives comment: What though, what does the job of a screening programme? The government should do it's best to spot treat and minimise the impact of this condition – this question is ludicrous.
P17	Affected Comment: I have known many men, family, friends and patients, taken way to early from prostate cancer. As a nurse I saw relatively young men die from this disease as it was picked up too late. Modern screening with MRI could prevent this and save lives and money. Discussion comment: I think its a poor decision not to screen. Recommendation comment: I think we should have screening. PSA, then an MRI if suspicious. It is wrong to not offer this when it is so devastating, often to younger men and their families. Alternatives comment: No. Screening as done in Sweden is how the UK should proceed. Anything else is ignoring responsibility.

P18	Affected Comment: Several friends and relatives Evidence Comment: The Swedish screening and MRI follow-up should be adopted in UK. Not enough MRI scans following raised PSA levels. 1 man dies every 45 mins from prostate cancer, screening could massively improve early detection and remediation. This is urgent and important – get round the false positives and reduce the fatal impact of prostate cancer. Discussion comment: Yes – a national screening programme for over 55 males is essential Recommendation comment: Yes it should because it can lead to earlier detection and hence treatment Alternatives comment: Develop a more reliable test asap. Get the team from Oxford on the case
P19	Affected Comment: Nope Evidence Comment: Please do not say no to prostate cancer screening. Norway and Sweden are doing it. Saying no clearly sends the message we do not want to spend money on prostate cancer screening. Saying no for the wrong reasons Discussion comment: Saying no for the wrong reasons Recommendation comment: It definitely should. The business case is already made in Scandinavia. Unless you think in the uk there are not humans living Alternatives comment: No substitute for screening programme. Only there are if you do not want to spend money. There are no substitute really Other comments:

	Start screening immediately

P20	Affected Comment: My dad had prostate cancer Evidence Comment: Early, curative treatment means fewer men requiring complex combinations of drugs and the spiralling costs of modern oncology. A targeted screening programme mirroring the risk-stratified approach used in Sweden, might cost ~£225 million annually. cut late-stage presentations by even 20% (and the evidence is, it would exceed that) the savings in avoided late-stage treatment and end-of-life care are also, a lot. Discussion comment: I have ***** brothers and as their sister I get regularly screened for breast cancer which ***** died of so that is another hormonal cancer in the family. Black men are twice as likely to get prostate cancer, so by not screening for this cancer I think there is a breach of our equality laws when there are several countries (Sweden and Germany) that do screen Recommendation comment: I think screening should be recommended for the reasons above Alternatives comment: Nothing as effective as screening and screening programs can be used to raise awareness
P21	Affected Comment: I have a friend currently undergoing treatment for prostate cancer, His was caught purely by accident. My husband had to argue with his GP for PSA screening- this should not be the case. If other countries can find a way to screen that is effective and worth while doing then so can the UK. We spend far too little on preventative medicine- it is time the NHS thought differently about healthcare Recommendation comment: it should be recommended- if other countries can find a way to do routine screening then we know it is possible and worth while doing. The UK need to factor MRI screening in as the next step to positive PSA results rather than biopsies.

Affected Comment:

My father had prostate cancer which was picked up through a raised PSA test (with no prior symptoms or family history), when he was in his early *****. He attended a free, charity led session where they were offering these blood tests to men within a certain age category- his result came back raised and he needed an MRI, where the cancer was detected. He needed a biopsy and it was found to be an aggressive type of cancer, requiring his prostate to be removed and subsequent radiotherapy. Thankfully, testing of the prostate showed they had removed all the margins and it had not spread or left any cancer cells behind. Sadly, we lost my father ***** , however we did get more time together with him, healthy, in the interim as a result of the PSA test he was offered.

Evidence Comment:

Whilst there can be some false positives and some missed through the PSA test- it is the best option we have to be proactive about preventative health then we should use it. As I highlighted this test picked up aggressive cancer in my father with no family history or symptoms, so likely outside some screening criteria, so it clearly has value. I believe most men would like to choice to 'opt in' to this screening (and potentially save their life), even if it meant potential diagnosis of a cancer that may not cause them a problem in their lifetime, and those who felt it too interventionalist would have the choice to opt out. With the NHS Long-term plan being about a focus on preventative help, this goes directly against that principle. It seems a money driven decision, and short sighted cost saving rather than rooted in a longer term investment. It goes against the European Cancer Screening recommendations and leaves men at a disparity to women's screening (breast and cervical) for example.

Recommendation comment:

Yes it should be recommended. Whilst there can be some false positives and some missed through the PSA test- it is the best option we have available. We need to be proactive about preventative health, not using it and doing nothing reads as the government not caring about the health of older men and those more at risk (BAME). As I highlighted this test picked up aggressive cancer in my father with no family history or symptom, so likely outside some screening criteria, demonstrating it clearly has value. I believe most men would like to choice to 'opt in' to this screening (which could potentially save their life), even if it meant potential diagnosis of a cancer that may not cause them a problem in their lifetime, and those who felt it too interventionalist would have the choice to opt out. With the NHS Long-term plan being about a focus on preventative health, this goes directly against that principle. It seems a money driven decision, a short sighted cost saving rather than rooted in a longer term investment. It goes against the European Cancer Screening recommendations and leaves men at a disparity to women's screening (breast and cervical) for example. It implies we are accepting of this type of cancer as an inevitable and acceptable consequence, we need to do better.

Affected Comment:

My husband and my son in law were both diagnosed with aggressive prostate cancer within weeks of each other ****. Both were caught by chance due to the persistence of their GP, who said that he had seen an increase in Prostate cancer in Asian men. He insisted on doing a PSA test, my son in law **** came back as positive and my husband **** was negative. His GP insisted on doing a physical examination as he explained in 20% of cases the test comes back as negative. The physical examination confirmed that there was a lump which led him to be referred to a consultant. Both of them then had MRI scans which confirmed cancer with a Gleason score of 8. Neither had symptoms. My husband completed his **** radiotherapy **** and my son in law had surgery ****. My husband and son in law are not related biologically and yet both have prostate cancer without any obvious symptoms.

Evidence Comment:

The committee considered Sweden and suggested the difference in demographics is a factor. Yes it is a very strong factor for screening. The UK has populations of higher risk of prostate cancer and death e.g. Black men. This evidenced and yet the evidence has been ignored in the recommendations.

Discussion comment:

Screening is absolutely necessary for men. Prostate cancer is a silent killer. My daughter and I could have been widows if it wasn't for a chance appointment and a persistent GP.

We know that not all GPs are the same nor are patients listened to about their concerns. Research shows on average it takes 8 to 10 appointments about a concern before a patient is referred and diagnosed with a cancer. The lack of screening for men leaves them at risk of death. This is no longer an older man's disease, it is affecting younger and younger men. The son of a friend has been diagnosed with prostate cancer at age ****. He is of Asian heritage too. So whilst South Asian men have been deemed as low risk, the current prevalence would suggest that this belief too needs to be questioned and actively monitored. Black men are at the highest risk and half of them will die. Mainly due to end stage diagnosis and advanced cancer. Regarding the argument of over screening/intervention this is nonsensical. From personal experience we know there are protocols in place which minimise unnecessary intervention and harm. No one questions the intrusive cancer screening women endure throughout their lives so why are we for men. Surely they too deserve equitable access to screening services to prevent the deaths of men. Especially now as the incidence of diagnosis and deaths in different populations of men is changing.

Recommendation comment:

Men deserve to have equitable access to screening services like women. Otherwise this is discriminatory. Black men are at highest risk of death from prostate cancer and yet there are no plans for screening them as a high risk group. Why? Again this stance is discriminatory.

Alternatives comment:

Tell us what those alternatives are.

It's too late if we are putting interventions in place after they have full blown cancer.

Other comments:

Identify those at risk either through the cancer gene screening or through proactive screening of men over 40.

If it's about cost please consider whether all men will be offered the cancer gene screening test. What is the cost of this? If it is not going to be widely offered to men then how is this equitable.

P24	Affected Comment: Yes, my father died with prostate cancer, spread and took him too early Evidence Comment: I know prevention is an added cost at a time when budgets are tight. We will not bring down expensive treatment costs if we don't go upstream and reduce demand. A life is lost to prostate cancer every 45 seconds. The PSA test might not be as specific as we would like however there are ways to qualify the false positives without biopsy/surgery (and the associated risks). This feels like a decision made based on political imperatives to reduce NHS spend when the only way to do that is reduce the demand which means more investment in prevention (as per the 10YP). Healthcare is an inelastic good, demand cannot be contained by price. Treatment of the sick in hospital takes up 94% of the NHS budget. We are not going to close down any hospitals and shift the funding into prevention anytime soon. All we can do, if we are serious about the NHS still being around in 10 years time, is to reduce the demand and lower the cost of treatment by catching problems early. This decision to leave things be is an example of words (in the 10YP) and actions being out of line. I tend to follow the actions as a guide to what decision makers really believe. Do the right thing, reconsider, put lives before money. Discussion comment: See above, request it is reviewed to put reducing avoidable deaths over money. Recommendation comment: Screen is necessary to reduce avoidable deaths and treat the condition early when in outcomes are improved and the cost of treatment is less. Alternatives comment: You could wait until men have it then spend a lot on chemo/radiology, hospital visits, palliative care. The current default. Perhaps start with high risk groups, black men, men over 60, whatever the data suggests would balance cost and risk. Other comments: See above

P25	Affected Comment: An uncle and my father-in-law both suffered with this disease. Discussion comment: A disgraceful conclusion, which smacks of political cost-saving at a time of massive pressures on existing waiting lists and a political reluctance to do anything which may add to that situation. Recommendation comment: Yes. Alternatives comment: “Ask your GP for a blood test” was met, in my case, with badgering and resistance.
P26	Affected Comment: Family members Evidence Comment: it appears that the committee did not take into account the evidence from countries who currently have targeted screening such as Sweden, Norway and Germany where modern screening has saved lives, money and avoided large numbers of false positives the committee has given for a reason to not roll out screening. It also failed to account for the higher numbers of black men in the UK who have a much higher risk of prostate cancer. Also, as far as i have been able to find, there were no black men on panel. while I'm not suggesting tokenism, lack of representation from the groups most affected seems like a huge omission Recommendation comment: It should, it will save a huge amount of money and human life in the long run

Affected Comment:

My husband ***** was diagnosed with Prostate Cancer after a high PSA result. He has a Gleeson Score of 8, following MRI and Biopsy.

The journey to diagnosis has been long and traumatic. ***** felt a lump whilst we were on holiday in July and went to the Doctors when we returned. Following a digital rectal examination of which the Dr said they weren't concerned, he requested for his PSA to be checked. 3 days post the test we received a call to advise he had a PSA count of 25 and a risk of Prostate Cancer. His previous PSA count in 2019 was 1.5, so this cancer has gone undetected for up to 6 years!

***** had an appointment with a consultant at ***** Hospital on ***** who took bloods and rechecked his PSA, which came back again at 25.

We then had an MRI scan ***** following the MRI, ahead of any call to discuss results ***** was called for a Biopsy, ***** almost 4 weeks post the MRI. This was an incredibly anxious time for us both, having to second guess results, use chat GPT to figure out that they had likely found tumours. We had to call and write to the hospital to ask if they had found something, 2 days after the appointment came through we had a letter to confirm suspicion of cancer, with the biopsy booked to confirm it.

Following the Biopsy ***** then received an appointment for *****! At which point we thought it can't be too serious as the appointment was a month away. We got a call to go to the hospital on ***** At which point we were advised that ***** had an aggressive Cribiform type of cancer and had to have a further PET Scan to see if the cancer had spread. So more waiting and stress and anxiety for us to see if ***** was going to have a death sentence.

We were advised at our appointment that the waiting time for a Prostatectomy on the NHS is 12-16 weeks! Those timescales to us are not worth the risk of cancer spreading. Given the months of stress, worry and anxiety we have already experienced we took a decision to go Private, ***** had a PET scan on ***** and received results on ***** to thankfully say it hadn't spread. We received the call with the same news from the NHS 9 days later! NHS again advised the waiting time for the operation would be 12-16 weeks, 12-16 weeks of not knowing if this cancer has time to spread and giving it time become terminal! Thankfully ***** had a Prostatectomy privately ***** which paid for, as ***** life is worth more to us than the waiting time. We are fortunate that we were able to financially do this. Given much longer the cancer would have been terminal

Evidence Comment:

The evidence missed is the stress, anxiety and death sentences awarded by allowing the cancer to become terminal. Without the PSA test, and another 3 months ***** would have had terminal cancer. My daughter would have been without a father, I would have lost a husband, his mother would have lost a son! My husband is *****!

The invasive testing post PSA was worth it! The diagnosis and form of cancer was accurate. Aggressive cribiform cancer!

It appears the recommendation is commercially driven rather than providing a pathway to protect men's health!

The cost of genetic screening to identify BRCA1 and BRCA2 is £2000! The cost of a PSA test, an early indicator of prostate cancer is £5! 400 men could be screened for the same cost as 1! Most men won't know if they have the gene.

It would only cost £6,000,000 to test all black men in the uk! Surely that is worth early diagnosis and saving lives!

Discussion comment:

I wholeheartedly disagree that PSA screening does more harm than good. Without this my husband would be living an unknown death sentence.

I know others who have prostate cancer and are on active surveillance. They would rather know and monitor that know too late!

The recommendation is appalling!

Screening people with a gene people don't know they have is an absolute cop out and will not go any way to screen those most at risk

Recommendation comment:

Screening should absolutely be recommended. Not only does it save individual lives it prevents families going through stress worry and anxiety of worry that the cancer has been caught too late. My family has been through hell and back this year. With screening the cancer would have been caught earlier and saved the stress and anxiety. Your report does not consider the impact to families and friends and loved ones of those affected at all!

Alternatives comment:

For the sake of mens health and their families start screening

Other comments:

Listen to the voices of those impacted. I don't know one person that has been on this journey that would align with this recommendation.

P28	Affected Comment: My stepfather died ***** from prostate cancer ***** after repeated visits to his GP. Screening would have arguably meant he would be alive today. Evidence Comment: I cannot understand how a detectable disease that kills a man every 45 minutes, the biggest killer of men, does not qualify for screening. I can only conclude that either the evidence was incomplete or the panel was ill-equipped to make such a decision. I understand that the panel of 11 consisted of 8 women and zero black men, despite being twice as likely as white males to die from prostate cancer. It's shameful. Discussion comment: The decision is, in my view, completely wrong. The risk of over diagnosis can be managed through the prioritised use of risk factors and high cost procedures (biopsy) reserved for the highest priorities. Saying no to even targeted screening of the highest risk groups is ludicrous; the only reasonable conclusion that can be reached is that the decision is racially motivated. Recommendation comment: Screening should be introduced because a) prostate cancer is the second most common cancer in the UK and b) almost 50% of these are diagnosed by chance. There are examples of other countries undertaking screening, with lower populations of high risk black or ethnic minorities. This makes no sense. Alternatives comment: No, screening is needed, given the high proportion of men who are diagnosed with no symptoms of prostate cancer; they are diagnosed by chance... Other comments: No.
P29	Affected Comment: Yes I am a prostate cancer survivor. It has had a profound impact on myself and family. While 'cancer free' each six monthly PSA check raises anxiety Evidence Comment: The recommendation does not appear to follow the evidence. The statistics clearly show early diagnosis saves lives. Targeted PSA testing will save lives – and avoid unnecessary interventions. Discussion comment: I have had prostatectomy following a symptom free diagnosis. However I do have family history both maternal and paternal. I only had a PSA check during an 50+ health check and only then

	after insisting that I was entitled to one- and even though the DSE examination suggested I had a normal prostate. The conclusion is wrong. A PSA targeted at high risk groups will save lives. Recommendation comment: Of course screening should be recommended as shown by the evidence! Alternatives comment: Really? The best way to help people is to screen. At some point in the future there will be better options for full screening. Until then the very least that can be done is to target screening to higher risk groups – all black men; men with family history and on request if you are showing symptoms. Other comments: Review the evidence and listen to men affected and also their loved ones.
P30	Affected Comment: My dad was diagnosed at ***** years old with no family history or symptoms. He was only tested as he requested the PSA test due to a relative on my mums side being diagnosed with stage 4. The gp initially declined as my dad was “too young” yet it was caught at stage 3. No man is too young. All men deserve the same screening levels for prostate cancer as women do for cervical cancer/breast cancer. Discussion comment: The recommendation is very disappointing especially since I now know of so many men who found out they have the cancer too late for it to be fully treatable. All men should have the option. Recommendation comment: Screening should be recommended. Men deserve to know their options around treatment. Women have a national screening programme for the most common cancers, why do men not have the same? Early detection is key to easier treatment – reducing the burden on the patients and on the NHS. Alternatives comment: Get a screening programme. Other comments: More disease awareness especially for black men who are at an increased risk.

P31	Affected Comment: Friends have been successfully treated, another at stage 4 may or may not see christmas Evidence Comment: The critical point seems to be that although the PSA test is notoriously given to false results it should not automatically lead to a biopsy. A scan would either validate a positive result or show that the PSA result was a false one. As a cancer survivor any delay in diagnosis or a wrong diagnosis steals life from the patient, Discussion comment: Black men and men with a family history are most at risk but under represented at the review Recommendation comment: Screening IF followed up by scanning positive PSA results would save many deaths and unneeded treatments. Waiting for a better test than PSA should not delay mass screening. Alternatives comment: As with all cancers early diagnosis and early treatment produces the best outcomes. Prostate cancer is often showing no symptoms until effective treatment is too late. Screening and scanning would prevent thousand of deaths and save a great deal of not requires treatment

P32

Affected Comment:

My grandfather had prostate cancer, my father died too young. I started requesting annual PSA tests when I was *****. When I was *****, the test showed raised level; my GP initially ridiculed me and the test as it was "notoriously unreliable" but reluctantly authorised a second one. This was higher, at which point he took it seriously. Biopsy, MRI and prostatectomy later, here I still am.

Evidence Comment:

The decision not to screen men is ridiculous, and flawed because it is based on past techniques and driven by the need not to spend money.

Discussion comment:

I repeat, the decision not to screen men is ridiculous, and flawed because it is based on past techniques and driven by the need not to spend money. At the very least, annual screening should be offered to men with family histories of prostate cancer and black men, who have proven higher risk levels.

Early treatment will save higher costs down the line

Recommendation comment:

See above.

Look at the Swedish model which is working and providing proper prostate screening and care.

Other comments:

Streeting should reject the recommendation not to screen.

P33	Affected Comment: It has not but we have lost friends to the condition leaving young teenagers with a father!!!! Evidence Comment: No comment Discussion comment: No Comment Recommendation comment: Yes and it seems crazy that this is one of the main cancers in the UK affecting the male population and the NHS is being passive about testing. We appreciate the Testing is not fool proof but a public screening program will pick up more cancers and make men think more about this issue and their health in general. All this will lead to catching prostate cancer in me much earlier, lead to better outcomes for them and their families and ultimately save the NHS a huge amount of money!!!! Alternatives comment: The screening program will force men of a certain age to start to think about this and as the male population does not mobilise as effectively and the female population a mandatory screening program is probably one of the only ways to get us being more proactive about this silent killer. Other comments: Yes run a UK and mandatory screen program for middle aged men and of course the men whose demographic and ethnicity much more susceptible to this disease.

P34	Affected Comment: Several of my friends have been treated for prostate cancer. Some died from the condition. Evidence Comment: No comments Discussion comment: I totally support the process. It is very important. It is also very important that interest groups which favour screening and which may have financial interests in diagnosis or treatment of cancer should not be given undue consideration during discussion of this review or its conclusions. Recommendation comment: Until it has been demonstrated in large scale RCTs that screening reduces all-cause mortality it should not be used. Screening that only reduces cancer mortality does not improve lives: it creates cancer patients. A diagnosis of cancer is inevitably frightening and treatment is hazardous. Quality of life is always impacted – even if adverse effects of treatment are relatively minor and short-lived. In the case of treatment for prostate cancer this is often not the case. There is considerable research evidence showing that, as a general principle, clinicians over-value the potential benefits of medical and surgical interventions and under-estimate their adverse effects. Most members of the public share this bias. Fear of cancer exaggerates it. There is still immense uncertainty around both the effectiveness and appropriateness of treatment for prostate cancer. In this situation, screening is potentially dangerous. Alternatives comment: Information campaigns and other interventions designed to persuade people to live healthy lives – to focus on general health rather than promoting fear of illness – could be far more beneficial in terms of improving both quality and quantity of life than screening programmes. Perhaps fresh fruit and vegetables could be subsidised? This would cost a lot less than a cancer screening programme! Other comments: Teach children to cook and to enjoy real food.

P35	Affected Comment: This condition has impacted my family and friends and the targeted screening that has been rejected would have delivered an early diagnosis and in turn a better prognosis. Evidence Comment: It seems that the diversity in the UK population has been used as a reason not to undertake targeted screening, despite this being the exact reason it should be undertaken. The evidence appeared clear, that black men are at a far higher risk of contracting prostate cancer as are all people with family history, knowing this and not screening accordingly simply leads to later diagnosis and more costly treatments and of course poorer prognosis. Discussion comment: I understand that money has to a consideration in every clinical decision however unpalatable I might find that, it's a practicality that cannot be avoided. It seems that in this case the maths are short term, not taking in to consideration the longer term impact. Citing the diverse nature of the UK as a reason not to undertake screening, when it is BAME groups that could benefit most appears as pandering to the right wing political agenda and I expect will be challenged. Recommendation comment: Screening should be recommended for targeted groups because there is sufficient evidence from other countries that this saves lives and reduces complexity of treatment, and ultimately cost. Alternatives comment: Given 50% of patients are asymptomatic until it is too late, I think screening is the way that the government could help the condition for those people, those who are symptomatic could also be helped with this approach plus improved health education.

P36	Affected Comment: Yes, I have been treated for prostate cancer and I am being followed up. I also have friends and acquaintances who have been diagnosed with the condition Evidence Comment: The evidence base was appropriate and complete as far as I am aware Discussion comment: I agree with the recommendation Recommendation comment: Population screening should not be recommended at the current time, given the gaps in knowledge and evidence. There are important studies currently being undertaken that will add to the knowledge base. But see below re values*. There may in future be sufficient evidence to recommend screening in certain defined groups or even at a population level if better diagnostic and risk stratification tests become available. * Given the current balance of risks vs benefits (and the risk of overdiagnosis) there is a need to better understand mens' values in this area. For example, it may be that most men would accept the risk of overdiagnosis (and overtreatment with recognised and significant side effects) if it meant that the cases of late diagnosis could be significantly reduced Other comments: See my comments above re mens' values in overdiagnosis vs late presentation

Affected Comment:

I am a patient survivor, diagnosed at age *****. I am the exact scenario this proposed policy ignores.

My diagnosis was aggressive: Gleason score ***** (*****). ***** stage (cancer extending into seminal vesicles), with extensive lymphovascular invasion. Crucially, I am BRCA Negative. I do not carry the gene mutation the NSC proposes to use as the gateway for screening.

Because my cancer was non-genetic but highly aggressive, a BRCA-only screening program would have excluded me. I would have been missed. My cancer would likely have been detected only after metastasis, at which point it would have been incurable.

Instead, I have had to endure a brutal multimodal treatment path to survive: radical prostatectomy, salvage radiation (halted due to severe toxicity), and ongoing hormone therapy. This has left me with life-altering complications, including ***** requiring multiple hospitalizations, and ***** with a ***** fracture.

This condition has not just “affected” me; it has dismantled and rebuilt my entire life. I am living proof that “high risk” is not synonymous with “BRCA positive.”

Evidence Comment:

The review places disproportionate weight on genetic evidence (BRCA mutations) while seemingly discounting the evidence for high-risk sporadic cancers.

The Definition of “High Risk” is Too Narrow: The evidence review relies on BRCA status as the primary proxy for high risk. This ignores the reality that the majority of lethal, high-grade prostate cancers (like mine) occur in men with no identifiable germline mutation.

Exclusion of Black Men: The review acknowledges the 1-in-4 lifetime risk for Black men but concludes the evidence is “uncertain.” Excluding a demographic with double the mortality risk because the data is “imperfect” is an evidentiary failure. The known risk should trigger a precautionary principle, not an exclusion.

Outdated Views on Harm: The evidence regarding “overdiagnosis” appears to rely on older, biopsy-first data. It does not sufficiently account for the role of modern mpMRI in triaging men before biopsy, which significantly reduces the diagnosis of insignificant cancers.

Discussion comment:

I strongly disagree with the conclusion that a targeted screening programme for non-BRCA men is not recommended due to the balance of harms (overtreatment) versus benefits.

The committee’s discussion focuses heavily on the harm of unnecessary biopsy or treatment of slow-growing cancers. It fails to adequately weigh the catastrophic harm of late diagnosis.

I am a case study in that harm. Because my cancer was aggressive, I required “maximal” treatment—surgery, radiation, and long-term hormone suppression. The toxicity I live with (radiation proctitis, fractures, loss of function) is the direct result of having to treat advanced, high-risk disease.

The recommendation to limit screening to BRCA carriers is effectively a decision to “ration” prostate cancer detection. It implies that unless a man carries a specific gene, his risk of lethal cancer is not worth the “cost” of screening. This conclusion abandons the majority of men who will die from this disease.

Recommendation comment:

Screening should be recommended, but it must be a risk-stratified programme for all men, not just BRCA carriers.

Why:

BRCA is rare; Cancer is not: Restricting screening to BRCA carriers addresses less than 2% of the population, leaving the 1-in-8 men (and 1-in-4 Black men) without a safety net.

Early Detection Equals Less Toxicity: If my cancer had been caught when it was Gleason *****, I might have avoided salvage radiation and the subsequent severe bowel injury and bone fractures. Screening doesn't just save lives; it saves quality of life by allowing for less aggressive treatment.

The Technology Exists: A protocol using PSA density followed by MRI triage is a viable, effective screening pathway that mitigates the risks of overdiagnosis cited by the NSC.

Alternatives comment:

If a full national screening programme is rejected, the NHS must implement a mandatory “Risk Assessment” at age 45.

Currently, men must ask for a PSA test. This relies on the patient being informed, which exacerbates health inequalities.

Active Case Finding: GPs should be incentivised or mandated to initiate a prostate health discussion with every man at age 45 (and 40 for Black men), rather than waiting for the patient to ask.

Access to MRI: Access to mpMRI prior to biopsy should be standardized across all trusts to reduce the harm of “blind” biopsies and overdiagnosis.

Education on “Silent” Risk: Public health campaigns must dismantle the myth that you only need a test if you have symptoms. My PSA was my only symptom; I felt perfectly healthy until I was diagnosed with high-grade cancer.

Other comments:

Do not wait for the results of the TRANSFORM trial (10+ years away) to update these guidelines. Men are dying today who could be saved by a risk-stratified approach using current technology.

I recommend an interim high-risk protocol that includes:

Immediate targeted screening for Black men, mirroring the recommendation for BRCA carriers.

A lower PSA threshold for referral in men aged 45-50.

We cannot allow “perfect” data to be the enemy of saving lives. I am living proof that young, non-genetic, high-risk cancer exists. Please do not finalize a policy that would have let me die.

P38	Affected Comment: I know a number of men who have had prostate cancer. Evidence Comment: Impact of risk stratification and evidence from elsewhere, e.g., Sweden appears to have been dismissed by the review panel. I understand there was no representation from black men on the panel from black men which feels like an oversight given their increased incidence of prostate cancer. Discussion comment: It appears that the review hasn't paid enough attention to those groups that have a higher incidence of prostate cancer, i.e., black men & previous family history. Recommendation comment: Screening should be recommended as early detection of prostate cancer will save lives, reduce costs by detecting the condition earlier, improve health & wellbeing and improve quality of life Alternatives comment: Use MRI scanning where indicated by raised PSA Use algorithms Increase awareness amongst men around screening

Affected Comment:

Yes.

Whereas I commend the committee's recommendation to initiate the targeted national prostate cancer screening programme to men with confirmed BRCA1 or BRCA2 gene variants every 2 years, from age 45 to age 61, I am disappointed that the committee are not recommending specific research into a more accurate test to the current PSA test, or to initiate a national population screening for this cancer.

In the past 15 years a significant number of my peers and acquaintances have succumbed to this disease with a lesser number surviving under treatment.

What I am aware of however, is the fact that the PSA test has resulted in the diagnoses for these survivors that I do know who are living with Prostate cancer, without which the likelihood of their survival is virtually nil.

Evidence Comment:

I would like to thank the Committee for the excellent work that they undertake in such a difficult fiscal climate, but request that population screening is initiated, in tandem with research into an improved PSA test.

It is surely relevant to note that Cervical screening is there for women (that is anyone with a cervix) between the ages of 25 and 64, when the %age of relevant population is significantly less than that of men succumbing to prostate cancer. Cancer Research state that There are around 3,300 new cervical cancer cases in the UK every year, that's around 9 every day (2017-2019) compared with over 63,000 men being diagnosed with prostate cancer each year.

Discussion comment:

As a layman I found the report very informative and am very aware of the difficult challenges that the committee have to address. I will remain very interested in this issue and look forward to ongoing discussion and further investment in research into improved tests for the incidence of prostate cancer.

Recommendation comment:

Yes. Screening should be recommended due to the large incidence of this condition in the overall population. I would request that this be the case for the Over 60's as a minimum but would be so much happier to see this initiated in the population over 50.

Alternatives comment:

I believe that greater general health awareness is required in the male population overall. This should be initiated at the earliest stages in life even in primary schools where minds are so much more receptive.

Further research funding is obviously needed but higher education research opportunities in the UK, once the envy of the world is woefully underfunded in this century.

This may be down to the short termism of political interests where government policy is designed for the short term and not looking towards providing greater opportunity to maintain a lively basis

of research and testing in epidemiological research or clinical exploration that will support exciting and lifesaving discoveries for the benefit of future generations.

Other comments:

Thank you for your time in reviewing this submission and I wish the committee every support in their work in the UK and for an objective discernment and wise adjudication by the members of all the issues that they deliberate over.

Yours Sincerely

P40	Affected Comment: I am at heightened risk of prostate cancer due to having Lynch Syndrome. Evidence Comment: Yes, it focussed on the BRCA gene for the genetic predisposition for prostate cancer, but not other genetic conditions such as Lynch Syndrome (particularly those with the ***** gene mutations). Discussion comment: Please include Lynch Syndrome as part of genetic predisposition to certain cancers, such as prostate cancer. Recommendation comment: It should be recommended for those with genetic predispositions, but you have only focussed on the well known BRCA genes. Alternatives comment: N/A Other comments: Yes, some genetic predispositions are not purely inherited/family history. Some are de novo mutations (first in the line). If already identified as having a relevant defective gene, those people should be included.
P41	Affected Comment: Yes Evidence Comment: I NOTE THAT 8 out 12 OF THE COMMITTEE ARE FEMALE I WONDER IF SUCH A GENDER BIAS IS PREVALENT ON COMMITTEES INVOLVED IN DECISIONS ABOUT BREAST SCREENING FOR WOMEN

Affected Comment:

Yes. If there were a screening programme in place the problem would have been detected earlier and major surgery and therapy avoided.

Evidence Comment:

What stopped the Committee reaching the same conclusions reached in other countries – a Prostate Cancer screening programme works and is cost effective?

The government claim to want a world class health service that we can be proud of.

This decision proves the contrary is true I.e. we are lucky we get a third world and third rate health service.

Perhaps the Committee should also have reviewed the evidence to support the continuation of the Breast and Cervical Cancer Screening programmes. Given the representation on the Committee I doubt they would have reached the same conclusion they have for prostate cancer.

Appalling does not do justice to the decision.

Discussion comment:

See the comments above.

This Committee had an opportunity to improve screening equality, give men at risk of and with prostate cancer the same chance and opportunity we afford women at risk of and with Breast and Cervical cancer. The chance of a better outcome for both the individual and their family.

Recommendation comment:

Yes.

Why? See above – equality, outcome, evidence from other countries e.g. Sweden and the real need to prove that our health service is not third rate and heading towards those of the third world.

It's called doing the right thing for the right reasons and not the wrong thing for the wrong reasons.

If the government and this Committee are brave enough perhaps the discussion should be about some of the things now done by the NHS using public money that it should stop doing rather than failing to start a game changing screening programmes. If you really want me to provide some examples I am more than happy to do so on request having spent almost thirty years in senior positions in the NHS I am aware of many examples of things that the NHS should not be paying for but does.

Alternatives comment:

The most cost effective process for almost any disease is prevent and then diagnose and treat early. Repeat.

	It is unlikely that we can prevent cancer occurring therefore the next most effective element of the process is early diagnosis and treatment – in other words a screening programmes. Why is the work being done on genetics if it is not about these two parts of the care pathway? Other comments: Have a proper public consultation about what the NHS will and will not do, what therefore has to be paid for by individuals either directly or via a repayable loan (similar to student loans) and what will be provided free at the point of delivery by a national health service. Reducing unnecessary variation by ensuring the same high quality training and development of all clinical staff is a fundamental building block of any national system and service. Another fundamental building block is the supply of more clinically trained staff than the NHS needs.

Affected Comment:

I have two friends affected by prostate cancer...one in their 70s and one younger person "diagnosed" in their 50s.

The younger man has been harmed....the PSA test was done without proper counselling and without a clear reason (in my view) he was monitored for several years with no treatment while all the time he and his family considered him to "have cancer" and be vulnerable and at risk. Eventually he had a prostatectomy I am still unclear if that was needed really.

The second man had a very raised PSA at a private medical screening and has had extensive medical treatment with side effects. I hope these outcomes will prolong my friends healthy life span but it seems very unclear whether that is the case as both have had side effects....both physical and psychological harms. In the case of the younger man this has extended to serious worry for his family members and created significant extra stress on the family. The publicity around screening seems to have been hijacked by those who know little about the harms of screening

Evidence Comment:

The NSC is to be commended for reviewing the evidence fully and carefully. I remain a bit concerned about the incidence in black men and its possible relationship to Vit D deficiency in that population. Where there is a positive family history in a black man this is a situation that requires individual counselling I suspect. This is not the same as a screening test applied in a blanket way.

Discussion comment:

I agree with the recommendations and its good that there is at last a fuller and proper study in the UK. The NSC should be firm in its messaging about the evidence. I would like to see improved messaging to stress the harms of screening and the robust approach needed., such as...

"In our pursuit of improving public health, it's critical that we base our decisions on robust, peer-reviewed evidence. While prostate cancer is a serious condition affecting many men, we must remain cautious and avoid interventions that could do more harm than good without solid proof of their benefits."

Prostate cancer screening typically involves a blood test for prostate-specific antigen (PSA), which can help detect potential signs of the disease. However, the effectiveness of this screening has been widely debated in medical circles.

Recent studies, including long-term randomized clinical trials, have shown that PSA testing does not significantly reduce prostate cancer mortality rates. In fact, overdiagnosis and overtreatment are serious concerns, leading to unnecessary biopsies, surgeries, and treatments that carry significant risks, such as incontinence, erectile dysfunction, and even death.

"Although some individuals may benefit from early detection, the overall evidence suggests that PSA screening could lead to harm in many cases," "The decision to screen should be based on an individual's health status, family history, and informed choice, rather than a blanket recommendation."

	Recommendation comment: at present the evidence simply does not support blanket screening. So no I do not think screening should be recommendedf Alternatives comment: More research a bout why its more common in black men...is it Vit D related? A more focussed approach with compulsory counselling and reading of information about harms. Much more publicity as above about the potential downsides of screening.which is rarely discussed. Other comments: Improve the NSAC messaging!! NSC always seems on the bck foot and needs to address peoples emotions and fears not just their rational decision making. Cancer is emotive.
P44	Affected Comment: I have been diagnosed with an enlarged Prostate and elevated PSA levels. I am on medication which has side effects. Alternatives comment: Funding more research to increase the accuracy of testing. Specifically to identify if, when cancer is identified, whether it is life threatening.

P45	Affected Comment: My partner had a routine PSA test several years ago and it was monitored. 3 years ago it was elevated significantly to warrant a referral to the urologist. The biopsy confirmed cancer and he then underwent a radical prostatectomy. The PSA test may not be perfect but it's all we have and it saved his life. Evidence Comment: If it's only going to be available for men with the BRCA gene or significant family history then how will these men know ?'will there be a screening program which will encourage men to be tested ? Discussion comment: Men must have access to the PSA testing. Recommendation comment: Yes. It's not perfect but it's all we have Alternatives comment: What are the alternatives to a screening program which?

Affected Comment:

I have prostate cancer, diagnosed as a result of regular testing. Fortunately the prognosis is that, being otherwise very healthy for my age, I shall die of something else, at a ripe old age, before the cancer can. I am ***** and so far the cancer shows no sign of accelerated growth.

Evidence Comment:

I believe the perceived inaccuracy of the PSA test is not a reason for it to be discounted. Whilst it might produce a number of false positives, follow up screening would show whether the result was correct and, whilst those scans cost money, where they catch the disease early, the resulting saving in treatment costs over those for catching it at a latest stage, would outweigh the diagnostic costs.

Discussion comment:

I believe the recommendation is shortsighted and that screening could save the NHS money by catching the disease early. It would reduce the cost of observation or treatment, which is likely, in many cases likely to be less radical and, therefore, less expensive than that required when the cancer is diagnosed at a later stage of its development.

Recommendation comment:

I believe that screening should be recommended. My own cancer was diagnosed early as a result of screening. My GP surgery offered an annual health check, from the age of 45, with a blood test for several conditions, including PSA for prostate cancer. I had those test for many years and, eventually, some ***** years ago, I was called to see the GP after such a test, with PSA reading slightly above the 4.0 threshold that was then considered a warning sign. Despite thinking this inexperienced GP was overreacting, I accepted the consultant referral. The consultant, despite his own reservations, ordered an MRI, which found suspicious cells and the diagnosis was confirmed by a biopsy. Fortunately in my case, as mentioned above, a later diagnosis would have made little difference but for others it could be a matter of life or death.

I was fortunate that my surgery had the policy of regular health screening for those approaching middle age. Many people could live healthier and longer lives were such screening the norm – and that extends to the sort of checks that I had, as well as prostate cancer.

P47	Affected Comment: Yes – father, and a friend Discussion comment: The recommendation is wrong and should be changed Recommendation comment: Definitely recommended as it will save lives, and early detection will cost the NHS less Alternatives comment: There should be a screening programme
P48	Affected Comment: Not applicable. Evidence Comment: None missed. Discussion comment: I feel very relieved that the National Screening Committee has not yielded to the campaign conducted in the Telegraph's and the Times's columns and that has arrived at its views after a long, cool, scientific and dispassionate look at the evidence. One would expect no less. Well done to it for ignoring the pressure sought to be put upon it. Political pressure has no place in the evaluation of the evidence as to benefits and harms. Recommendation comment: Your decision on screening Brac1 and Brac2 cases is correct. Your recommendations not to screen other cases for the time being, but to await data from the Transform Trial, is also correct. Alternatives comment: As the Winton Centre for Risk, Cambridge to produce a tool/document for men to show the statistical outcomes for having a psa test when not previously diagnosed with prostate cancer, showing the benefits and harms, including false negatives and false positives, so that public misunderstandings of the merits and deficiencies of the psa test as a screening too can be better understood. Other comments: No

Affected Comment:

My father's best friend died in his late forties after having prostate cancer. He was not diagnosed until it was too late.

Evidence Comment:

I welcome the review's consideration of current evidence, particularly regarding the limitations of PSA testing. However, I believe several important areas of evidence were under-represented or not fully explored:

a) International models of risk-adapted prostate cancer screening

Countries such as Germany, Sweden, and Norway are already moving toward PSA-based, risk-adapted screening pathways that include MRI as a secondary test. Early evaluations from these countries show:

- * earlier detection of clinically significant cancers;
- * reduced diagnosis of low-risk disease due to MRI triage;
- * improved stage at diagnosis, which strongly influences survival.

The review appears to give limited weight to these real-world data. The review considered that the population in these countries is too different to the UK. These countries have fewer minority ethnic groups. So the UK has a higher proportion of groups that are at risk. If these countries can justify targeted screening with a lower risk population, it would make sense that the UK would do as well?

b) Emerging evidence on targeted screening for high-risk groups

There is substantial evidence that:

- * Black men have roughly double the risk of developing prostate cancer and a higher mortality rate;
- * Men with a first-degree relative with prostate cancer have a significantly elevated lifetime risk.

Despite this, the UK NSC review focuses largely on universal screening trials rather than risk-stratified approaches, which are increasingly recognised internationally as a way to improve benefits and reduce harm.

c) Advances in MRI technology and diagnostic pathways

Recent studies show that MRI-first pathways can substantially reduce unnecessary biopsies and overdiagnosis which would address one of the main concerns traditionally raised against screening. The review acknowledges MRI accuracy but seems to rely heavily on older trial data that predate widespread MRI use.

d) Under-representation of cost-effectiveness models that include long-term savings

Several cost-effectiveness studies suggest that earlier detection reduces the need for expensive advanced cancer treatments. If such models were considered, they do not appear to have been emphasised.

Discussion comment:

While the caution shown by the UK NSC is understandable, the conclusion seems strongly weighted toward the historical limitations of PSA testing rather than the modern diagnostic pathway combining PSA, MRI, and targeted biopsy.

The review also does not sufficiently address the ethical or equity issues around maintaining the status quo, particularly for higher-risk groups who currently face worse outcomes and lower awareness.

Recommendation comment:

I believe the UK should recommend risk-adapted prostate cancer screening, not universal screening.

Reasons:

- * Equity: Black men and men with a family history face significantly higher risks; a “no-screening” policy affects them disproportionately.

- * Modern diagnostics reduce harms: MRI-first pathways dramatically cut overdiagnosis compared with the older trials on which many conclusions rely.

- * Real-world evidence supports feasibility: Other European healthcare systems are already implementing versions of risk-based screening with promising outcomes.

- * Long-term economic benefits: Early detection reduces the incidence of metastatic disease, which is substantially more expensive to treat.

The recommendation should therefore be updated to reflect contemporary evidence and the successes of risk-stratified screening models abroad.

Alternatives comment:

If a full screening programme is not recommended, the UK should still implement meaningful steps to reduce late-stage diagnoses:

a) Proactive awareness campaigns for high-risk groups especially targeting:

Black communities

Families with a history of prostate cancer

Men aged 45–70

b) A structured “informed PSA testing” pathway in primary care, ensuring that all GP practices:

- * offer PSA testing to high-risk men without barriers;

- * provide standardised information about risks and benefits;

	* have clear referral pathways for MRI before biopsy. c) Expand MRI capacity: If MRI is critical to reducing harms from screening, adequate MRI access is essential. d) Pilot regional risk-adapted screening programmes This would allow collection of UK-specific data rather than relying on older, non-UK evidence. Other comments: * For the UK to commission new research specifically evaluating risk-adapted screening, including PSA combined with genetic, family-history, and demographic risk factors. * The decision-making process should explicitly address health inequalities, which are central to prostate cancer outcomes. * Ensure transparency around economic modelling, including long-term cost savings from avoiding late-stage treatments.
P50	Affected Comment: I've had friends with prostate cancer and had a scare myself Evidence Comment: Not medically trained so would not know Discussion comment: I have had prostate cancer scares and tests and MRI have ruled it out for now but am now regularly monitored. This was only picked up originally because of a water infection. It is a scandal that as a country we still do not have a national screening program in place for a cancer that kills Recommendation comment: It should be recommended to save lives. If a high psa level is found an mri can rule it out

P51	Affected Comment: I am writing as part of a movement at ***** School, *****. As a collective we have all been impacted by cancer and prostate cancer is particularly important in our community. We all know someone, or of someone, effected by this horrible disease. Evidence Comment: We trust in the evidence provided by the experts and believe this should be supported and funded by our government. Discussion comment: The screening programme is well thought through with incremental stages which ensure funding goes to those who need it. It is important to families who have lost people to cancer that they see everything being done to stop the same happening to others. The specific age group shows that there is obviously a need to support people in that category. It is clearly evidenced by the NSC with the genetics identified and the process is set out for how we can catch cancer earlier. Recommendation comment: Yes, Cancer kills and this will save lives. Alternatives comment: We believe you should follow the expert advice. Other comments: We recommend that the government fund the programme and that people who require screening are identified quickly and efficiently.

Affected Comment:

I received treatment for prostate cancer in ***** and consider myself to be one of the lucky ones. I was able to benefit from someone else's misfortune. After a businessman in ***** died as a result of prostate cancer, his widow decided to invite a team of nurses, administration staff and a doctor to visit the town every 2 years to offer screening against the disease. This screening was not organised through the NHS but by the ***** Hospital near *****. Despite requiring a financial donation to cover costs, these events were extremely well supported. (Frequently men were queueing out of the door before being able to enter the venue). To my mind this suggested that there was need for screening on a regular basis. GP surgeries didn't advertise the fact that PSA tests were available let alone at regular intervals. My own PSA results were less than 1 for several years, but in ***** they produced a reading of *****. By the following year my PSA was ***** , sufficient to be referred to hospital for my cancer journey to begin.

It started with biopsies and an MRI scan to confirm that I had a small amount of cancer which was thought to be slow growing. The advice, which I followed, was for me to go on "Active Surveillance" with regular PSA tests with a further set of biopsies after 12 months. These later biopsies and a second MRI scan showed that there was more cancer present and it was growing more rapidly. Now was the time for action whilst the cancer was still contained within the prostate gland. Regardless of how unpleasant the tests may have been, I felt that it was preferable to the alternative i.e. death. I received extensive information regarding the pros and cons of surgery and radiotherapy.

It is suggested that the PSA test is not very reliable but surely it is the first indicator so other tests can be carried out. Tests for other cancers are not 100% accurate either. Surely it is time to start a screening programme to see if we can reduce some of the 12,000 deaths per year as a result of prostate cancer.

I benefitted from a screening programme, so why can't other men be offered the same opportunity.

Recommendation comment:

Screening should definitely be recommended. It is the first step in diagnosis.

Alternatives comment:

Anything is better than nothing. Improvements to the screening process will occur in the future but we should use what tests are available now.

Other comments:

Why has it taken so long to even consider introducing a national screening programme for prostate cancer?

P53	Affected Comment: No, but 75 years old male so in the frsme Discussion comment: UKNSC has got the right balance. Recommendation comment: Screening should NOT be recommended. Inadequate test. Overdiagnosis and over treatment. Personal choice not more State vontrol Alternatives comment: There are alternatives already in place – see GP. Other comments: Far too much State control already,

Affected Comment:

This submission of mine will be specifically about BRCA based screening. Later on I will make a different submission about a different area of the guidance.

Although I have had prostate cancer and I will talk about that in a different submission, right now I would just like to point out that I have no idea if I have the BRCA gene. My mother died of *****. But I have no idea if she had a BRCA gene test because she is dead and I can't ask her.

Evidence Comment:

BRCA-based screening can unintentionally exclude people on lower incomes and those from Black backgrounds because access to earlier genetic testing in the UK has not been evenly distributed. Historically, BRCA testing was offered mainly through breast and ovarian cancer pathways used more often by White, higher-income women who had clearer documented family histories and better access to specialist services. Lower-income groups and Black families were less likely to receive referrals, partly due to reduced engagement with genetic services, fewer recorded family histories, and structural barriers such as transport, time, and awareness. As a result, BRCA status is known disproportionately for people from higher-income and White backgrounds. If a prostate cancer screening programme relies on "known BRCA mutation status" to trigger enhanced monitoring, it will systematically advantage those groups and exclude many Black men and low-income men who may carry BRCA mutations but have never been tested.

Discussion comment:

I believe that the the process of using BRCA to identify people for screening is ineffective and naive.

The Sky News interview with Prof Mike Richards at 16:00 just after the guidance had been published tore him apart on this issue.

First of all, you would have to have your relative being young enough and living in the right place to actually have had the BRCA gene test. Secondly they would have had to been informed that this is an important thing to pass on to their siblings and children, and they would have had to have done so. And thirdly the potentially effective man has no evidence in his hands that the bracket gene was found. Is there a test certificate that he could produce for his sister's test?

Recommendation comment:

Professor Mike, Richard seems to explaining that this will be a passive process rather than people being tested for the BRCA gene proactively. Is this going to be available to men on request if they want to find out in their own blood tests when they see their GP? From what I can understand that is not the case.

Alternatives comment:

A screening program is something that will be applied consistently throughout the whole population, regardless of income, education, social grouping or race.

At the moment having a higgledy scrum of men being turned away by their doctors, even when they are at high risk is what we are seeing.

Other comments:

As far as the BRCA tracing is concerned, if it's not going to be proactive then this will have very little impact. I don't know where the 20,000 cases figure comes from. Is this 20,000 women and others with cancer who have already been noted with the gene?

Affected Comment:

I have been personally diagnosed with prostate cancer.

In this response to your consultation, I want to focus on the COST elements and the assumed model for future screening. I realise that cost at present is not the main driver for the recommendation in the report not to screen.

However, I am concerned that you may be baking in several assumptions about how a screening programme would be delivered, and that those assumptions will then become "reality" over time, instead of starting from a more modern, lower-cost approach. A GP-led, venous-draw model is inherently expensive and is not used, for example, in bowel cancer screening, where home kits are the norm. So this particular response focuses on COSTS and the assumed model for future screening.

Evidence Comment:

I could not see any explicit modelling of home-based PSA pathways (for example fingerprick kits collected at home and returned by post). This is a serious omission because both uptake and cost per test might look very different, and more favourable, if home sampling were used.

The evidence base does not consider the potential role of simple lateral-flow PSA self-tests as a pre-triage step. These already exist in the retail market at low cost and, in my own case, a home lateral-flow PSA test was the trigger that led to a diagnosis of stage 3B prostate cancer.

The model fixes uptake at 36%, derived from older trials using surgery-based venous draws, but does not appear to explore what uptake might be under a modern, home-testing model that greatly reduces time and travel burdens. This is particularly important for lower-income, time-poor men who are least able to attend GP appointments.

The evidence tables seem to give limited prominence to patient-reported outcomes and lived experience of over-treatment, especially the long-term harms of prolonged androgen deprivation therapy and the lack of routine quality-of-life monitoring in current practice.

I could not see a detailed health inequalities analysis comparing different sampling routes (GP surgery venous draws versus home tests). This matters because the choice of route may significantly affect who gets tested, who is diagnosed early and how existing inequalities in prostate cancer outcomes evolve.

Discussion comment:

Good point. I've removed that bullet from this answer and kept it as a separate worry, as you asked.

Q3. Do you have any comments on the discussion, conclusion or recommendation in the review?

(Focus: costs, practicalities, implementability)

The discussion appears to treat the current PSA testing pathway (venous draws in GP surgeries, low uptake, traditional referral routes) as fixed, and then mentions disproportionate costs as a secondary supporting factor in the overall recommendation that screening is marginal or not justified. This risks turning today's relatively expensive, GP-led service configuration into a permanent constraint, rather than asking what a more practical, lower-cost, home-testing pathway could look like.

The focus on BRCA1/2 carriers does not grapple with the practical difficulty of identifying those men in real life. It assumes a long chain of events: a relative must have had cancer in a setting where BRCA testing was done; that relative must understand the implications; they must inform their siblings or other relatives; those relatives must then act on that information, book an appointment and successfully persuade a doctor to arrange testing; and finally they must retain paperwork or proof of carrier status in order to access a screening programme. In many families paperwork will be lost, relatives may be estranged and conversations about inherited cancer risk may never happen, so real-world uptake of a BRCA-only programme is likely to be much lower than the theoretical at-risk population.

The report relies on an assumed 36% uptake of screening invitations but does not fully confront what it means in practice to design a programme that fails to reach nearly two thirds of the target population. The discussion could be clearer that alternative, more practical models, including home-based testing, would change this fundamental exclusion of segments of society at the same time as reducing cost.

Overall, the discussion and recommendation feel cautious about changing clinical practice but not ambitious enough about changing the delivery model and testing route. A fuller consideration of costs, practicalities and implementability might support a different conclusion about how best to design a modern, risk-based and accessible prostate cancer testing pathway.

Recommendation comment:

Here is Q4 with that last sentence rewritten:

Q4. Do you think screening should or should not be recommended? Why?

I think screening should be recommended in principle, but only if it is designed around low-cost, home-based testing rather than the expensive GP-led venous-draw model modelled as the only option in the report. A programme that starts from surgery-based blood tests will always look marginal on cost grounds and will miss large parts of the population (because the NHS decides it can only afford to target part of the population, and also because many time-pressured and sceptical segments of society will not respond if a GP appointment is required in person).

A more cost-effective and practical approach would be a tiered pathway: first, a cheap home PSA test (for example a lateral-flow or simple fingerprick kit); second, for those with an abnormal result, a confirmatory lab PSA using a fingerprick sample returned by post; and only then, if still raised, referral for MRI and targeted biopsy. This would reduce the number of venous draws and clinic visits and would lower total programme costs.

Home tests would also improve uptake, especially among lower-income, time-poor men who struggle to attend GP appointments. That is important for both value for money (because fixed costs are spread over more participants) and equity (because it avoids concentrating benefits on those who already use healthcare services most).

A GP-led venous-draw screening model, as costed in the report, is both expensive and difficult to scale. It risks consuming primary-care capacity and embedding a design that is hard to change later, which is not an efficient way to introduce what is, in effect, a new national testing offer.

By contrast, a home-testing-first screening recommendation could be implemented more flexibly and at lower marginal cost: pre-triage 5-minute lateral flow test kits can be mailed centrally, follow-up triage home collection kits then mailed out (to those that report positive lateral flows), processed in existing laboratory infrastructure to produce a numeric PSA result which then can be triaged into low risk, medium risk and high risk (for no immediate action, periodic surveillance or calling in for an MRI).

For these reasons, I am concerned that the cost-related comments used as secondary support for the current recommendation are implicitly biased against a screening programme because they use the most expensive screening model to result in the worst cost assumptions. They implicitly equate “screening” with a GP-led venous-draw model, and there is a real risk that this will become the fixed template for any future screening proposals, crowding out cheaper and more practical home-testing-led designs right from the start.

Alternatives comment:

Here is Q5 with your new first bullet added and the rest kept, slightly tightened to fit the “costs / practicalities” theme:

Q5. There could be many alternatives to a screening programme. How else do you think the NHS or the government could help people with the condition?

Develop a simple app and web-based data collection service so that men can log urinary symptoms, fatigue and other relevant signs, record whether they have BRCA-positive relatives, note which relatives (to their knowledge) have died of prostate cancer, and provide more accurate ethnicity details (for example mixed heritage and whether a Black parent was the mother or father). This low-cost, real-time dataset would allow the NHS to target information, testing offers and follow-up to those at genuinely higher risk, including men whose risks are not obvious from existing NHS records.

Guarantee a clear right to a PSA test on request for men in relevant age and risk groups, with a standardised information sheet on benefits and harms. This is relatively low-cost but prevents men from being turned away or discouraged when they proactively seek testing.

Make subsidised or free home PSA tests (both 5-minute lateral flow and home collection kits) widely available through pharmacies and online ordering. This would be much cheaper than a GP-led venous draw model and would help men who struggle to get appointments, especially those in lower-income and time-poor groups.

Use national campaigns to promote a simple, low-cost “check and confirm” pathway: lateral flow pre-triage at home, followed by a postal lab PSA if the first test is positive, and only then referral to MRI where appropriate. This would normalise testing without committing to a fully GP-delivered screening programme.

Improve post-diagnosis support and monitoring, including routine quality-of-life questionnaires during treatment (for example for fatigue, mobility, sexual function and mood) and clear referral routes for problems such as DVT or severe hormonal side effects. Better processes, rather than large new budgets, could prevent avoidable harm.

Provide GPs with clear decision-support tools and national guidance on how to respond when men bring in home PSA results (for example from lateral flow or postal kits), so that those results are not dismissed but are triaged consistently and efficiently into MRI or watchful waiting. Fund and fast-track implementation research into low-cost, home-based PSA pathways (including their impact on inequalities), so that future recommendations are informed by real data on what is practical, affordable and acceptable, rather than by the single, expensive GP-led model currently used in the costings. Other comments: I will respond separately on clinical overtreatment disbenefits. The UK NSC should explicitly separate “test choice” from “delivery model” in future work, and model several delivery options side by side (GP-based venous draws, home lateral flow, home fingerprick, community phlebotomy) so that cost conclusions are not locked to the single most expensive route. The next phase of work should include a short options appraisal comparing: (a) no screening, (b) BRCA-only screening as currently proposed, and (c) an app data collection and risk assessment led pathway with Two-Stage home-testing PSA triage using lateral flow pre-triage plus home collection kits. Each should be costed transparently so that ministers and the public can see the trade-offs. The committee should commission a formal health inequalities impact assessment for different testing routes, with a specific focus on lower-income, time-poor men, so that future recommendations do not unintentionally widen the outcome gap between professional groups and those in more precarious work. Future modelling reports should include a short, non-technical “assumptions summary” which spells out, in plain language, what has been assumed about who takes blood, where tests are done, how invitations are issued, and what follow-up looks like. This would make it easier for lay responders to suggest credible, lower-cost alternatives. The UK NSC should set a clear timetable and trigger criteria for revisiting the recommendation (for example, after specified milestones in TRANSFORM and other key studies), so that the current, GP-led cost structure does not become entrenched by default. Patient involvement should be broadened to include men who have: * self-initiated testing using home PSA routes * entered the system late because of access barriers * experienced significant harms from over-treatment. Their experience is essential to designing a pathway which is both cost-aware and practically workable for the full range of men the NHS serves.

P55	Affected Comment: Yes, a family member Evidence Comment: I think the evidence failed to note that now with PSA tests, MRIs and risk stratification there is less chance of harms by testing. If men are left to be picked up too late stage 4 they will cost the NHS more never mind the poor reduced quality of life they will have. Discussion comment: I don't understand the current conclusion and recommendations especially when compared with our European counterparts. Recommendation comment: Yes, it will save lives and reduce treatments and cost down the line. Alternatives comment: There is limited treatment for Stage 4 Prostate cancer. Screen and treat appropriately. Other comments: The decision should be changed.
P56	Affected Comment: I had a mastectomy myself in ***** so pushed my husband to request his very first PSA test at aged ***** – no family history. Thus came back at ***** and further tests followed (albeit very slowly over 4 months sadly). Prostate removed ***** – no nerve sparing due to extensive localised cancer also into bladder neck. Early days. Post op PSA ***** so to be redone in a month. Not sure if I hadn't pushed him to have a test where we would be – he had NO SYMPTOMS at all – getting up to pee once in the night. Ridiculous no screening approved. Recommendation comment: Recommended as my husband had no symptoms whatsoever

Affected Comment:

My younger brother died of Prostate Cancer in ***** age *****.

We had no family history and he is white british.

He did not have the BRCA gene (tested just before he died)

he detected symptoms over ***** and couldn't get a GP appointment. He had stage 4 cancer that spread very quickly despite an expensive ***** hormone treatment agreed by CCG. It spread to his peritoneum and he eventually died of sepsis in pain and with no adequate palliative care in hospital. They wanted to record his death as metastatic prostate cancer but we insisted that sepsis which was not recognised by the GP be added to the death certificate. He died in pain and very distressed due to inadequate care in hospital ***** currently a Trust rated as inadequate for many years and subject to the***** enquiry *****.

If he had been screened aged 50 he might be alive now.

How will his son access screening as he also doesn't "fit" the screening criteria and will have to await symptoms which will be too late like his father.

YOU NEED TO REVERSE YOUR SCREENING DECISION AND DO THE SAME AS OUR EUROPEAN COUNTRIES ON SCREENING AND THE USA.

Evidence Comment:

You need to consider how many other European, Scandanavian and North American countries are offering screening – are they all wrong are you are right. I don't think so!

Discussion comment:

The conclusion is wrong.

My brother is example of how you can't shoe horn screening into ethnicity, genetics, family history, age. He fitted none of that criteria – see my comments in box 1

If you can't consider that, consider this – he left an ***** son who can't access screening under your conditions.

You have one less tax payer to contribute to your welfare spending.

Recommendation comment:

Screening SHOULD be done with the use of MRI if you worried about over diagnosis.

Survival depends on catching it before the silent killer slips into your life... sets up base camp, tiptoes around your system and squeezes the life out of you.

Roughly half of prostate cancers are diagnosed by chance.

The other half present with symptoms, often at a more advanced and dangerous stage... and too late.

In other words, without organised screening, men are left to rely on luck.

The UK National Screening Committee has said 'no', to targeted screening even for the men most at risk...black men and those with a family history.

Their predecessor committees have said no since 1997.

It's hard to see how this latest conclusion is right.

The Committee's first line of argument is that prostate cancer screening risks 'overdiagnosis' and 'overtreatment.' An argument that is over-the-hill.

Stuck in the PSA tests of the 1990s... too many false positives, too many biopsies, too many harms caused in the quest to avoid harm.

That world has gone.

Modern risk-based approaches... don't biopsy everyone with a raised PSA... they're MRI'd, risk-stratified and the majority left alone.

Sweden, Norway, parts of Germany are doing this. Their data shows what ours would show... target-screen fewer men 'unnecessarily', catch more cancers, treat fewer late-stage cases.

Mike Richards (he also chairs the chaotic CQC) headed the committee, (as far as I can tell; eleven people, eight women and no black men?), that dismisses lessons from Sweden.

Apparently, the population there is 'too different'... code for fewer minority ethnic groups.

There is an irony in that conclusion. The very groups that make England different are the groups at higher risk... black men who have roughly double the incidence and double the mortality.

If Sweden can justify targeted screening with a lower-risk population, how can England justify refusing it in a higher-risk one?

Late-stage prostate cancer is brutal. For him, our family... and the Treasury.

Treatment for advanced disease includes long-term hormone therapy, repeated imaging, radiotherapy, chemotherapy, palliative interventions, end-of-life care.

Early, curative treatment means fewer men requiring complex combinations of drugs and the spiralling costs of modern oncology.

Family history is vital. In medical terms, family history is well accepted as;

'... first-degree relatives (father, brother, son) with a diagnosis of prostate cancer, sometimes extending to second-degree relatives, grandfather...'

Targeted testing would have caught it, long before.

Risk calculators, guidelines, international screening protocols, Sweden, the US, and NICE, rely on this family definition. No ambiguity.

A targeted screening programme mirroring the risk-stratified approach used in Sweden, might cost ~£225 million annually.

	It's a lot but... ... cut late-stage presentations by even 20% (and the evidence is, it would be exceed that) the savings in avoided late-stage treatment and end-of-life care are also, a lot. Why the reluctance? Prevention requires money now. Science increasingly favours risk-based screening. Everything we need; PSA, MRI, risk-stratification algorithms... all exist. Screening saves lives Alternatives comment: Its obscene that you would not Tax the top 1% of our country who can afford private screening, to provide screening to those most likely to be effected and most likely to be unable to afford screening. Get your act together and provide adequate screening, treatment, palliative care for those you can't treat because its too late. We are the one of the richest country in the world
P58	Affected Comment: yes Evidence Comment: without involving patients and public more, how can anyone possibly know if the potential harms are seen in same way to men as they are to committees making decisions. Many may see the potential harms as a price well worth paying to lessen risk of dying from prostate cancer. Its patronising to be making that decision for all men. Men need to be treated as equal partners to those making these decisions and many more ways other than just this late consultation found to hear their voices and really understand what they see as unwanted harms versus a risk worth taking etc. Recommendation comment: Yes, it should be recommended.

P59	Affected Comment: My husbands father and brother both had prostate cancer. Despite this family history my husband was not offered screening and the GP was reluctant to send him for a PSA test, only doing so when he had clear symptoms of blood in his sperm. He was then diagnosed with prostate cancer which had already spread outside the prostate. If routine screening had been in place for people at high risk like him we wouldn't be in the situation we now find ourselves in. Evidence Comment: Whilst I understand the financial implications of testing I am not sure there has been full research into the cost savings from reducing the number of late stage diagnoses and palliative treatment Discussion comment: Accuracy and new methods of testing are advancing rapidly and I do not think a final conclusion should be made at this stage. There should be better guidelines and alerts put in place for men at high risk so they are given a choice as to whether to undergo further testing or not Recommendation comment: It should be recommended. See above comments Alternatives comment: Better public information and education, including clearer guidelines for GPs when considering risk. Research funding for genetic predisposition and simple low cost tests (saliva test etc), prevention etc
P60	Affected Comment: My husbands father, and my father. My husbands father passed way from prostate cancer and due to certain symptoms I worry my husband will be prone to the same disease. Equally, I have a brother and worry about whether he too may be likely to have prostate cancer due to our father's illness. Screening might just make the difference and I am surprised that there isn't already something in place. Recommendation comment: I think screening should be recommended. If due to funding it can't be made available to everybody, perhaps those with a family history could be considered, although I appreciate this would mean it would remain a cause for concern for many others. Alternatives comment: If any science is known about nutrition and how this can make a difference, perhaps an education programme could be considered.

P61	Affected Comment: Yes, my father has survived Prostate cancer – He lives in ***** and his was detected at an early stage at his annual health check where he is offered a PSA test among other diagnostics. And I also fear for my husband's health in the future. Evidence Comment: Modern risk-based approaches don't biopsy everyone with a raised PSA. They're have an MRI scan, are then risk-stratified and the majority would be left alone. Sweden, Norway, parts of Germany are doing this. Their data shows target-screen fewer men 'unnecessarily', and then catch more cancers early and so then have to treat fewer late-stage cases. This would pay for the screening programme. Discussion comment: A man dies of Prostrate cancer every 45 minutes. The impact on families is devastating. Recommendation comment: I think screening should be offered to men in the high risk groups, i.e. black men and men with a family history. Alternatives comment: See above. Other comments: No.

P62	Affected Comment: A family member has died. Evidence Comment: I can't see anything missing but the interpretation seems odd. Germany, Norway and Sweden are screening and it is working, but we can't compare them as their population is too different. The difference being that our population is more at risk. Surely that means that we should be doing what they do!? Discussion comment: Germany, Norway and Sweden are screening and it is working, but we can't compare them as their population is too different. The difference being that our population is more at risk. Surely that means that we should be doing what they do!? Recommendation comment: Yes I do because the evidence shows it would pick up cancers earlier which would save lives and reduce late-stage treatment. Alternatives comment: A media campaign to raise awareness and encourage people to get screened. Other comments: No
P63	Affected Comment: Lots of friends affected. Evidence Comment: Should consider the long term cost of treatment, rather than catching it early. Recommendation comment: Should be recommended due to lack of obvious symptoms. Often too late once identified.

P64	Affected Comment: A close friend died of this condition approx 10 years ago. Evidence Comment: I think greater weight should be given to more modern and reliable ways of screening for this disease. It does not need to be j which is non-intrusive and easily done. Sweden can do it why not the UK? Discussion comment: Research the methods used elsewhere in the world to ensure UK is aware of the cutting edge of this work, not using old methods. Recommendation comment: Yes – it s a huge killer of men, can be spotted by suitable diagnostics. The human cost of not screening is too high. Treatment options are varied and can be more successful if done early in the diseases's course.
P65	Affected Comment: Yes, absolutely, this condition has affected me. Evidence Comment: Yes, the feelings of the two men that you were going to save but now are not in your recommendations. Discussion comment: The Screening Committee is mostly women, that's excellent for considering women's breasts but not for a man's prostate. Has any male member of the committee got prostate cancer? If so he would be an expert. I'm assuming the woman on the committee don't have a prostate, but in this day and age who knows. Recommendation comment: A PSA test should be offered to all men over 45. It's taken a long time, basically through men of note, getting this disease and bringing it into the public domain. Shame on the NHS. Ten years ago I thought PSA was a Public Service Announcement.

Alternatives comment:

Just offer the PSA test and start saving lives, it's simple.

The time has long passed when the NHS and the government should have helped Men in this country... it's not People.

Other comments:

Sure...

P66	Affected Comment: My father died from Prostrate cancer spreading into his bowel 9 years after his clinician identified it but felt it would be intrusive to operate when it was slow growing. I was asked by ***** whether I wanted to be tested. After discussion with my GP, I decided to, with a negative PSA result Evidence Comment: I didn't see any research into higher risk groups such as myself with a close relative who had had the disease. My GP practice is very active in referring for diagnostics on possible cancers and I have had test for six possible sites and types, all of which were benign. I agree with this approach Discussion comment: I would like to see targeted screening for those where a close relative has had the disease, together with a discussion with the GP about potential risks Recommendation comment: On a targeted basis or those where a close relative has had the disease, together with a discussion with the GP about potential risks Alternatives comment: Better understanding of the different types of the cancer (slow growing or not) and of the effects of treatment. More research on MR and CT screening and how to improve its efficacy Other comments: No

Affected Comment:

I had a radical prostatectomy for prostate cancer ***** years ago.

Biopsy was a challenge but it's an unpleasant afternoons work.

Evidence Comment:

I feel you have over egged the side effects of surgery (impotence and incontinence). Yes I leak tiny amounts of urine but almost certainly no worse than women who have given birth. Sure immediately after surgery it's much worse but settles and is completely manageable. I don't stink of pee or have wet underpants but when you say incontinence that is what people imagine and perhaps you do to. What time post op did you analyse the incontinence risk??.

Impotence risk is a possibility and took a year for me to recover but it's not the end of the world and you have not put this into context of the age of men and women affected and you have weaponised this threat. We are not talking about men in their twenties and whilst men in their 50-60s think they are still 20 they are not.

You have also completely ignored the intractable inconvenience to men of having even a benign enlarged prostate and the other benefits of surgery Urology wards are full of men having prostate misery sorted out. I have the flow of a donkey, no hesitancy, no urgency, no prostatitis and no urgency. If someone rang me to say they got the histology wrong and I never needed such surgery I would say it transformed my life and please thank the histologist. It took 24 hours in hospital, pain less than an appendectomy. Yes having a catheter in for 7 days was miserable but no big deal unlike my elderly uncle who almost certainly has prostate cancer and has suffered a catheter for the last ***** miserable years and will die with the wretched thing. I am cured, discharged and have no miserable prostate problems/TURP to deal with. What a result!!.

Discussion comment:

You have approached this area with a very narrow field of vision and have been defeatist and timid in your thinking.

I have ended up talking to three men about surgery verses radiotherapy. All of whom were frightened of surgery but after discussion all went for it and are like me chuffed.

Sure radiotherapy and hormones might be right if you are very frail but no man wants to be without testosterone.

The surgeons will get better and better. Build a prostate surgery factory in the middle of the country and bus people in and that will reduce the cost and improve the results.

Recommendation comment:

Yes of course.

What's the alternative. Let men die unnecessarily ??. Zero progress.

The informed will simply pitch up at their GPs for PSA check anyway and plug themselves into services leaving the most vulnerable to suffer and get second rate treatment quietly as men do.

So the result will be chaotic fragmented services rather than planned progress.

	You have the opportunity to mechanise the whole process and do something truly radical which will be cheap and effective and world leading. If it doesn't work it's easy to close down and you will have the data to confirm this. We will spend more on chaos in the long run. Alternatives comment: Chatting therapy?? Palliative care??? Endless poor treatment (chemo, radiotherapy, hormones) options as people die or suffer with prostate symptoms. No save this money and mechanise it all into something that will work Other comments: We have bad outcomes for so many cancers because we dither and don't diagnose it early. Looks like you will follow suit. Stop fretting about side effects which men will dismiss and deal with rather than dying.
P68	Affected Comment: I lost a nephew at ***** years of age, my brother, his father has had his prostate and bladder removed due to cancer Evidence Comment: You need to screen patients with family history of prostate cancer too Discussion comment: As above Recommendation comment: It should, as soon as possible Alternatives comment: Screening is the best way forward

P69	Affected Comment: Yes my father died of prostate cancer Evidence Comment: The evidence I based on old data before the widespread use of targeted testing and MRI Discussion comment: Yes the recommendations are being made by a totally unrepresentative group of people. Let them review the breast screening programme and see what the data show! Recommendation comment: It should be recommended as the cancer is easily treated at an early stage and is a silent killer Alternatives comment: It couldn't screening is imperative Other comments: The money saved by screening and early intervention not only saves lives but also money

P70	Affected Comment: My uncle died of prostate cancer about *****. He was diagnosed late and was unfortunate to pass away as it was too late to treat him. Evidence Comment: I have a cousin who lives in ***** and he tells me that they have a risk based screening programme. Yes, there was over diagnosis in the old days but now with risk based protocols, this should not be much of an issue. As a black man at high risk, I would think the screening should be available in the UK as in Norway and Sweden. Discussion comment: I think the recommendation to implement a risk based screening programme will be right decision. There is a higher proportion of ethnic minorities in the UK compared to Sweden, and if they find it worth while to screen, then it would be the same in the UK. Leaving men to be diagnosed of prostate cancer by chance is worse risk than the fear of over diagnosing them. Catching the disease late will also be more costly to treat. HMG is emphasizing more prevention than treatment and for prostate cancer, this is exactly the opportunity to do just that. Recommendation comment: I definitely think the screening must be recommended. Alternatives comment: Risk based screening will definitely be cheaper than the late diagnosis by luck alternative. Other comments: Please help men get diagnosed early by recommending the screening.

P71	Affected Comment: I have no family history of prostate cancer. However, the planned link with offering testing for men who have tested positive for BRCA 1 or BRCA 2 is unhelpful. Discussion comment: The current rate of testing for BRCA 1/2 is poor in the general population and the wait for a referral to clinical genetics for testing is many months, if not years whilst the risk continues of potential aggressive cancer. The lack of indication of the link with the other BRCA cancers is not helpful to the general population and must be made far clearer. The lack of offer to black men is a shocking indication of institutional racism and desperately needs amending – (I am white). Recommendation comment: I agree that a national screening programme per se is not appropriate, but having a wider screening now should be available whilst Prostate Cancer UK trial is established and reports in 2-3 years time as to what is the most appropriate methodology going forward Alternatives comment: There is such a ground swell of public opinion that something needs to be done and I'd agree that a limited offer is appropriate but it does need to include family history, genetic risk and ethnicity to stop the perception that the NHS is institutionally racist. Other comments: No
P72	Affected Comment: Friends Evidence Comment: They are wrong in rejecting the targeted screening approach used in other countries which has shown to Catch prostate cancer early Recommendation comment: Evidence from other countries is that screening can be effective. Leaving things to chance condemns many men to a poor end of life (and an expensive one for the NHS) Alternatives comment: If the government is too mean to do screening, they should at least encourage all men to have a PSA blood test on a regular basis

Affected Comment:

Yes, in 3 ways.

1. My father in law aged *****, died of prostate cancer 6 weeks after we were married in ****.

2. My husband aged *****, was diagnosed with Aggressive prostate cancer. He opted for a radical surgical option, as a father of ***** beautiful children aged ***** and happy married. Difficult choices but we did not wish to err on the side of caution and see an unnecessary relapse. It was successful. 6 months later, he was back working in the *****.

3. My husband aged *****, was diagnosed with a occurrence of the prostate cancer, somehow and to our enormous shock. He was treated with radiotherapy successfully and has been well since. He retired from the ***** aged *****, as a *****, much liked by his teams of staff in *****.

If we were not waiting for it, due to family history, it was almost missed. We persuaded our Gp to do oncology route first, based on symptoms & history. We are ***** and our GP was good: he listened! We were lucky.

Our son is ***** now and looking to start his own family. Please review your current stance and recognise the value of screening and family history, to save lives. My son is important!!!!

Evidence Comment:

I am sure there will be better placed organisations to answer this than I.

I just wish to ask. That any approach that is adopted is both an evidence based design one where service users are involved in a meaningful way. Not after the decisions have been made.

Discussion comment:

I totally disagree and hope you will review and bring about a national targeted screening programme. Inclusive of those 8 in high risk subsets and family history of the disease

Recommendation comment:

Yes. I do.

Targeted screening will save lives.

It will reduce the cost to the Treasury in the long run maybe not so in this parliament.

But essentially, we must take that long view. If we are serious about having a healthy work force to enable to improve the country 's economy.

Alternatives comment:

Provide hubs in primary care with a preventative Lead...with work related workshops, for all. To understand the value of having checks done.

Ask survivors to speak to hospitals to help improve their services.

Other comments:

	No.

Just keep it simple.

Affected Comment:

While I approach this consultation primarily as a matter of public health equity, I do so with a deep personal understanding of its implications. This is not an abstract issue for me. My lived experience with elevated prostate risk, shared with many others in my community, means that the policy decisions made here will have a direct and tangible impact on my own health journey and that of my family. This is precisely why I believe so strongly in a system based on equality. When two groups face comparable levels of risk, granting structured healthcare access to one while withholding it from the other is not merely a clinical discrepancy—it is a personal injustice that affects real people, their well-being, and their future. I urge the committee to see beyond the data to the human consequence of creating a two-tiered system and to correct this inequality in the final recommendation.

Evidence Comment:

Consultation Response: The Inequity of the Risk Group Selection

Subject: Consultation Response – ***** The inequity in the draft prostate cancer screening recommendation.

To: The UK National Screening Committee,

I am writing to express a fundamental concern that the draft recommendation creates an unjust and illogical inequality between two high-risk groups.

1. The Draft Policy Creates a Direct and Unfair Disparity.

The Committee acknowledges that both men with BRCA1/2 gene variants and men of African and Caribbean descent are at significantly and similarly elevated risk of aggressive prostate cancer. Yet, the policy proposes a targeted screening programme for one group while explicitly rejecting it for the other.

This creates an indefensible two-tier system:

- Group A (Included): A man of Ashkenazi Jewish heritage (a population with a high prevalence of BRCA variants) can access screening through the genetic pathway.
- Group B (Excluded): A Black man, with a comparable level of risk derived from robust demographic and clinical evidence, is told he is not prioritised.

A GP will have the discretion to offer a test to the first patient under the “genetic risk” banner, while being bound by national policy to deny a targeted pathway to the second. This is not equitable.

1. The “Missing Evidence” Argument is Flawed in This Context.

The consultation documents cite “lacking and uncertain” evidence for screening Black men. This justification fails when the policy simultaneously advances screening for another group with comparable risk.

The issue is one of consistency and principle. If the bar of evidence is met for one high-risk group, it must be applied equally. To do otherwise is to make a value judgement that one

group's risk is more valid or actionable than another's, which is unacceptable in public health policy.

Furthermore, the committee's own risk assessment appears outdated. It heavily weighs the harms of overdiagnosis based on old diagnostic pathways. Modern NHS practice, using an MRI scan before biopsy, has been shown to halve overdiagnosis and reduce unnecessary biopsies by 90%. This modern safety net fundamentally changes the risk-benefit calculus for all high-risk groups, making the exclusion of Black men even less justifiable.

1. This Decision Will Cement and Widen Existing Health Inequalities.

The 2025 National Prostate Cancer Audit shows that survival inequalities for Black men are already widening. A decision not to include them in a targeted programme is not a neutral "wait-and-see" position; it is an active choice that will perpetuate and worsen these documented disparities.

I urge the Committee to rectify this inequity in its final recommendation. The policy must either:

- Formally include men of African and Caribbean descent as a named, high-risk group eligible for targeted screening, or;
- Provide a clear, public, and ethically defensible rationale for why two groups with comparable risk are being treated so differently.

A policy that creates one hidden pathway for some and a visible barrier for others fails the basic tests of fairness and transparency.

Discussion comment:

Subject: Consultation Response: Draft Recommendation for Prostate Cancer Screening *****

To: The UK National Screening Committee

I am writing to express a significant concern regarding the equity of the draft recommendation for targeted prostate cancer screening.

- The principle of screening high-risk groups is correct, but the current proposal creates a two-tiered and inequitable system.
- It establishes a pathway for men with BRCA variants (a genetic risk group) while explicitly excluding men of African and Caribbean descent (an ethnic risk group), despite both having a comparably elevated risk.
- This creates an unfair outcome:
 - Men from ethnic groups with high BRCA prevalence (e.g., Ashkenazi Jewish) gain access via a "concealed" genetic pathway.
 - Black men, with risk based on demographic evidence, are publicly excluded from a targeted programme.
 - This grants clinicians unacceptable discretion and obscures the policy's demographic impact, undermining transparency and fairness.

I urge the Committee to ensure the final policy in March 2026 addresses this by either:

1. Formally including men of African and Caribbean descent as a named high-risk group, or
2. Providing a clear, public rationale for prioritising one high-risk demographic over another.

To proceed otherwise would sanction an inequitable health policy.

Yours sincerely,

Recommendation comment:

No, a national screening programme should not be introduced in its current form, as its design institutionalises a profound and unjustifiable health inequality.

The fundamental flaw is that the proposal creates two distinct classes of high-risk men. It grants a formal screening pathway to men with BRCA gene variants—a group which includes many men of Ashkenazi Jewish heritage due to that population's higher prevalence of these variants. At the same time, it explicitly denies the same structured access to men of African and Caribbean descent, who face a comparable and well-documented elevated risk of aggressive prostate cancer.

This is not equitable. It means a man of Ashkenazi Jewish background can be offered a screening test by his GP under national policy, while a Black man, with a statistically similar level of risk, can be told he is not a priority. The policy thus creates a hidden, privileged pathway for one demographic while erecting a visible barrier for another. This is unacceptable.

Therefore, I cannot support the introduction of a programme that would actively worsen health disparities. Screening should only be considered if it is redesigned to be truly equitable, by explicitly including men of African and Caribbean descent as a named, high-risk group with equal access. The current draft fails this basic test of fairness.

Alternatives comment:

Beyond the urgent need to rectify the inequity in the current draft recommendation, the Government and NHS can and must take immediate, concrete actions to address prostate cancer disparities in an equitable manner. These actions should be implemented regardless of the final screening decision.

If a targeted programme is implemented, equity must be its foundational principle. This requires:

- An Integrated, Named Risk Framework: The programme must explicitly name all high-risk groups—including men of African and Caribbean descent and men with a family history—alongside those with BRCA variants. A single, transparent eligibility list prevents hidden pathways and ensures consistent application by all GPs.
- Proactive, Standardised Invitation: The NHS must move from passive “informed choice” to proactive, direct invitation for all eligible men, using primary care records to identify them by ethnicity and family history, just as it would for genetic data. This eliminates reliance on patient awareness or GP discretion, which currently drives inequality.
- Community-Designed Communication: All public information and invitation materials must be co-designed with communities facing the greatest health inequalities, particularly Black communities, to ensure they are accessible, trusted, and effective.

If a national screening programme is not approved, the Government must implement an alternative National Targeted Case-Finding Strategy. This should include:

1. Mandatory GP Education & Guidance: Issue immediate, mandatory guidance requiring GPs to initiate risk conversations with all higher-risk men at age 45. This must be supported by compulsory training to ensure every GP understands ethnicity as a major risk factor, countering the current inconsistent practice.
2. A Funded National Awareness Campaign: Launch a sustained public health campaign, co-produced with and targeted at Black communities, to communicate their elevated risk and the right to a PSA test via the GP.
3. Utilise Existing NHS Frameworks: Apply the NHS Healthcare Inequalities Reduction Framework directly to prostate cancer. This would mandate local "health equity audits" of testing pathways and require Integrated Care Systems to develop and fund plans to reduce late diagnosis in Black men.
4. Accelerate Inclusive Research: Prioritise funding and support for trials like TRANSFORM that are specifically designed to generate the evidence needed for equitable screening protocols, ensuring future decisions are not delayed by a lack of data.

The current approach of excluding named ethnic risk groups while including genetic ones is administratively and ethically flawed. Equity must be designed into the system from the start, not added as an afterthought. Whether through a formal screening programme or a robust case-finding strategy, the tools to act fairly and save lives are available now.

Other comments:

Recommendations for an Equitable Approach to Prostate Cancer in the NHS

Given the UK NSC's draft decision, which risks institutionalising a health inequality by including one high-risk group (men with BRCA variants) while explicitly excluding others at comparable risk (Black men and men with a family history), immediate and proactive steps are required from the Government and NHS. The following recommendations are offered to ensure a fair and effective system.

1. Mandate Proactive, Equitable Risk Assessment in Primary Care.

As a national screening programme is not yet recommended for all, the onus for early detection falls on primary care. The current system, which relies on men knowing their risk and requesting a test, demonstrably deepens inequalities. Therefore, the Government must issue mandatory guidance for GPs and Primary Care Networks (PCNs) to proactively identify and initiate risk conversations with all higher-risk men. This should use a clear, risk-stratified approach:

- Proactively contact Black men aged 45+ and men with a family history aged 50+.
- Ensure administrative and clinical staff are trained not to be "blockers" to PSA test requests from informed, higher-risk men.
- Implement SNOMED coding to audit these conversations and ensure equitable reach.

1. Launch a Co-Produced, Targeted National Awareness Campaign.

Persistent low awareness, particularly in high-risk communities, is a major barrier. Nearly 75% of men do not know what the prostate does, and half believe they would be invited for a test if they

were at risk, leading to dangerous inaction. The NHS, supported by government funding, must launch a sustained public health campaign co-designed with Black communities and relevant charities. This campaign must move beyond symptom-based messaging (as early prostate cancer often has none) to focus on individual risk and the availability of the PSA blood test, directly tackling fear and misinformation.

2. Enforce the Use of Existing NHS Frameworks to Tackle Inequality.

The NHS already has tools that must be applied rigorously to prostate cancer. The Core20PLUS5 framework specifically targets health inequalities and includes early cancer diagnosis. Integrated Care Boards (ICBs) must be directed and resourced to use this framework to:

- Conduct local “health equity audits” of their prostate cancer diagnostic pathways.
- Develop and fund specific action plans to reduce late diagnosis among Black men and those in deprived areas.
- Support community engagement, working with grassroots organisations to build trust and share information.

1. Accelerate and Fully Support Inclusive Research.

The decision to await more evidence for Black men must be met with an urgent, well-funded effort to generate it. The Government must ensure the landmark TRANSFORM trial—specifically designed to tackle inequalities and recruit a representative cohort (at least 10% Black men)—is fully supported and that its findings on high-risk groups are fast-tracked for review. Furthermore, investment in “real-world evidence” projects focusing on Black men’s outcomes should be prioritised to build a robust case for policy change.

equity must be engineered into the system. The alternative—a hidden pathway for some and a visible barrier for others—is clinically unjust and erodes public trust.

Affected Comment:

All African-Caribbean men SHOULD be routinely screened at the age of 40-45 if they have a male family member who has had prostate cancer!

At 50 if no family history!

Go/NHS should update current computer system to integrate all red flags(family history,to include ALL cancers and colonoscopies in both male and female family members)

To use the simple test to reduce false positives(I have put together an easy template available upon request) Simple low to no cost.

The above questionnaire negates all previous surveys,the facts are readily available,saves money,time,lives

The questionnaire I have created minimises the false positives,there isn't any other effective method of testing for prostate cancer,PSA test and MRI currently the best method!Neither cause harm and both are beneficial WHEN done early enough!!!!

Evidence Comment:

I do,it's biased!

Don't recommend screening Black men!!!!

Who are twice as likely to be diagnosed later and have a worse prognosis than white men!
(Prostate cancer UK) 1 in 8 white men are diagnosed with prostate cancer 1 in 4 African/Caribbean men are diagnosed with prostate cancer,later thus worse prognosis than!!!!

Don't recommend targeted screening of men with family history!

Offer a targeted national BRCA1 or BRCA2 gene variants screening every 2 years, from age 45 to age 61 (so ALL men are screened for the gene) Prostate cancer is in the top 3 killers of men in the United Kingdom! Early screening is Vital!

Discussion comment:

When was this discussion,where is the conclusion available????

Recommendation comment:

It should be,as my previous notes explain!

Also as someone living with prostate cancer !

It will save lives,which is what the NHS does,public not private(prove it is not about money!!!!!!!!!!!!!!more funding for the NHS,less Bureaucracy have the NHS Governmentally ran,stock bought at cost not inflated by companies to make money,the cost savings would be enormous!!!!!! NO PPE scandal here!!!

Alternatives comment:

	Currently there isn't much more that can be done apart from the questionnaire that I have previously mentioned to vastly reduce the false positives tests!!! It's about people NOT money!!!! There are other treatments available from private healthcare providers,that also happen to be in NHS hospitals,but only available if you can afford to pay!!!!!!*****!!!
P76	Affected Comment: No not directly. Evidence Comment: If other countries, for example Sweden, successfully and continue to have evidence supporting their screening programme then that should be enough for us to invest in order to save lives (and longer term resources). I also understand that the UK has a higher risk population than the likes of Sweden. Discussion comment: It needs to be changed so that we have a system of screening higher risk groups in the population. Recommendation comment: It should be recommended. Alternatives comment: Follow what has worked elsewhere eg Sweden.

P77	Affected Comment: Im 60 currently having issues,im facing surgery on monday i was tested aged ***** only found out recently. Recommendation comment: 100% should be happening.
P78	Affected Comment: My brother died ***** from advanced, metastatic prostate cancer. He had missed early signs and was beyond any hope of cure whdn his cancer was detected. He also had ***** and ***** which also limited the options for managing his condition. Evidence Comment: Not evidence missed, but a lack of diversity and representation on the decision making committee. Discussion comment: Evidence from other countries increasingly shows the benefits of screening based on a PSA test and risk stratified MRI scanning; Sweden being the clearest example of this. Sweden has less ethnic diversity than the UK, so a lower proportion of black men, who have a significantly higher risk of developing and dying from prostate cancer. It is reasonable to assume that the benefits of screening would therefore be greater in the UK. Recommendation comment: Screening should be recommended. Whilst the cost of a screening programme is significant, the savings in cost and time of treatment, together with preventing the loss of productivity by sufferers will more than balance this. My brother received many months of very expensive symptom management and palliative care, without any prospect of a cure. Far better to have spent this money on earlier screening and less expensive treatment that probably would have offered a cure. Alternatives comment: Clearly ongoing information and publicity will help, but will never match the benefits of an established screening programme. Other comments:

	Not a recommendation, but a request. My brother's treatment options were limited by his pre-existing dependence on ***** drugs to manage his *****. Please ensure the commitment to developing new drugs that improve treatment for *****.
P79	Affected Comment: I have seen a number of friends who have been diagnosed with prostate cancer. One man dies every 45 minutes. Roughly half of prostate cancers are diagnosed by chance. The other half present with symptoms, often at a more advanced and dangerous stage... and too late. Other European countries are using risk-based approaches, yet England still relies on old data on which to make decisions. Testing and screening is vital if we are to stop this deadly killer. Invasive biopsies can be avoided in many cases through the use of MRIs. I suspect that the reason for this refusal to implement a risk-stratified is one of requiring money up front when the benefits to men, the UK economy and the NHS is further down the line. The Government must take a longer term view or else it will fail men's cancer. Recommendation comment: Other European countries are using risk-based approaches, yet England still relies on old data on which to make decisions.

	Testing and screening is vital if we are to stop this deadly killer. Invasive biopsies can be avoided in many cases through the use of MRIs. I suspect that the reason for this refusal to implement a risk-stratified is one of requiring money up front when the benefits to men, the UK economy and the NHS is further down the line. The Government must take a longer term view or else it will fail men's cancer. Other comments: Implement a risk-stratified approach to screening as undertaken by other countries.
P80	Affected Comment: Yes, my husband Recommendation comment: Should definitely be recommended, men need to be made aware of the fact that it's a simple blood test. Alternatives comment: Men should be invited for screening as women are for cervical screening.
P81	Affected Comment: Yes. I am aware there are concerns re known gene variant of BRCA1 and BRCA2. My family are affected by the CHEK2 gene variant. Family members have suffered or died from multiple cancers including those of the breast and prostate. Might CHEK2 be considered for inclusion in the screening criteria? Thank you, *****

Affected Comment:

Yes, I have prostate cancer that was diagnosed in ***** (aged *****) after a GP suggested a PSA blood test – I had no symptoms. I had the op, followed by chemo and am on life time HT – as it had spread to lymph nodes. Diagnosis was too late for it to be cured. My cancer was aggressive and, if not found, would have spread and killed me.

Evidence Comment:

I am not an expert with statistics and so could not follow EQ-5D (page 15 of the narrative). However, it seems to say that if cancer is found and treated then in many case the treatment is unnecessary as the cancer would not have killed the man. To me, with two *****, this is scientifically flawed. How, if radical treatment is undertaken, can it be assessed that the treatment was not necessary and the person would have survived? It is not possible to “test” non-treatment – as you cannot go back in time.

Discussion comment:

The CEO of PC UK said tonight that, in essence, the screening committee were saying that for 100 men, 2 would die and 20 would have unnecessary treatment.

Firstly, who is deciding the treatment is unnecessary?

Is it unnecessary if the man does not die from prostate cancer?

If I had not been tested, I would have died.

As I was tested, I have not died – so would I be classed as receiving unnecessary treatment?

I would have been perfectly happy to have had the PSA blood test, the biopsy and MRI scan and be told I did not have cancer.

Recommendation comment:

I definitely think it should be recommended.

2 men (out of a hundred) dying undiagnosed is not balanced by 20 (supposed) men experiencing some sort of harm through being tested.

In the current environment, I do not see how men are overtreated – with PSA, biopsy, MRI and bone scans and expert MDTs to review the evidence and recommend appropriate treatment.

Alternatives comment:

Make sure that the guidance to GPs from the Office for Health Improvement and Disparities which includes the phrase “The PSA test is available free to men who request it.” is widely circulated to GPs

<https://www.gov.uk/government/publications/prostate-specific-antigen-testing-explanation-and-implementation/advising-well-men-about-the-psa-test-for-prostate-cancer-information-for-gps><<https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.gov.uk%2Fgov-ernment%2Fpublications%2Fprostate-specific-antigen-testing-explanation-and-implementation%2Fadvising-well-men-about-the-psa-test-for-prostate-cancer-information-for-gps&data=05%7C02%7Cuknsc%40dhsc.gov.uk%7Cb95da540bc3b4ec847c908de31dec61f%7>

	C61278c3091a84c318c1fef4de8973a1c%7C1%7C0%7C639003030040884988%7CUnknown%7CTWfPbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIIYiOilwLjAuMDAwMCIsIIAiOiJXaW4zMilslkFOIjoiTWfPbCIsIldUljoyfQ%3D%3D%7C0%7C%7C%7C&sdata=gLyfxW%2FxEwmwJLfVqJzpX3gMY19gmFOea6lyapb3IQ%3D&reserved=0> This would prevent GPs turning men away in the mistaken belief that early prostate cancer has symptoms – which it does not. Other comments: Please do not balance a larger number of harmed men as having the same “weight” as a smaller number who would die. Place little weight on supposed cost-effectiveness (4.9, page 16) of screening – as this did not seem to reflect the later costs of treatment and care (including terminal) when it was not diagnosed early enough.
P83	Affected Comment: Prevention is far better than prolonged treatment and in the long run far cheaper. Screening should be available for high risk groups at the very least. The NHS ten year plan makes reference to keeping people healthier and preventing ill health. Screening for prostate cancer can be a reliable, cost effective means of maintaining health and preventing disease, with all the benefits, both in terms of using NHS funding wisely and effectively and avoiding unnecessary deaths and suffering. Evidence Comment: Data from other countries such as Sweden shows that screening can be effective, targeted and cost effective. Discussion comment: The recommendation of the review looks short sighted and taken for immediate financial reasons. The cost of a screening programme would be easily offset by longer term savings in treatment. Recommendation comment: Screening should be recommended for at least high risk groups, and then a wider programme.

	Alternatives comment: A targeted awareness and promotional campaign aimed at those most at risk.
P84	Affected Comment: Family members affected directly and indirectly, and only by luck was a PSA conducted that led to diagnosis relatively early. Evidence Comment: Some of the evidence from other countries seems to be dismissed based on grounds of 'different population'. That's irresponsible – find more applicable comparator data, or set out to create our own datasets! We already know more about vulnerabilities and likelihoods e.g. for some ethnic groups, so instead of a blanket decision follow the evidence that some targeting at least would be appropriate! Discussion comment: PSA alone is too blunt a tool – but this is 2025 where other risk factors, family histories, ethnicity etc can all provide a more targeted approach to screening. The investment in these would no doubt provide significant returns in reducing longer-term treatment and support costs, as well as improving quality of life and longevity for the individual. It just needs to be a decision completely removed from short-term politics! Recommendation comment: It should be recommended, but it doesn't have to be a blanket screening using purely PSA or 'traditional' methods. It's nearly 2026 – time to take a modern view. Alternatives comment:

	By preventing the condition, or catching it early. And worryingly this question refers to 'the government'. Which one? This one, or the one we'll have in the next few years? Or in 20 years when I'll be in the most likely age group for prostate cancer? Should I just 'hope' that it will be sorted by then, or should we be making decisions now that might not fully provide benefits for a few years. Please, please divorce these questions from 'government' and make them about evidence and innovative scientific research. Other comments: Governments shouldn't make health policy. They should make the best of ACTUAL recommendations and evidence from the experts, regardless of whether they will be the ones in power when the credits roll.
P85	Affected Comment: My partner was screened for prostate cancer fortunately it was clear. My father was screened and had it. He lived. Evidence Comment: The screening my partner underwent involved a blood test and then a small operation. It was a relief to know that he did not have cancer. Discussion comment: I think the conclusion is fundamentally flawed. I know prostate cancer can be Recommendation comment: I think screening should definitely happen for those who are high risk (black men for instance). It appears to be discriminatory when countries with lower levels of higher risk men provide a screening service. Men are notoriously difficult to reach too. Alternatives comment:

	In addition to screening there should be more about symptoms so families can be aware of when to seek help.
P86	Affected Comment: My partner's father was recently diagnosed and is imminently due to have surgery to remove his prostate. He had no symptoms and requested a PSA test as a precaution due to his age. Following MRI and further testing a tumour was discovered which otherwise would have gone unnoticed. Evidence Comment: This feels like a short-term cost saving exercise rather than a long-term solution. Is this due to a lack of diagnostic equipment and trained professionals rather than an evidence-based approach? Perhaps as a targeted programme for at risk groups might be of benefit rather than a blanket giving up. Lots of men die from preventable prostate cancer that would have been caught earlier if screened. Discussion comment: I disagree with the recommendations, screening programmes are used in other countries with more homogenous populations, we should be keeping up with these rather than dropping them! Recommendation comment: Screening should be recommended, as detailed earlier. Alternatives comment: Such as what exactly? By the time symptoms are felt, it is often too late. Palliative care and late stage treatment will cost the tax payer more than a robust screening programme

	Other comments:

Perhaps reviews should be led more by independent experts rather than treasury focused cost savings.

Affected Comment:

I am a ***** year old Prostate cancer survivor, post-prostatectomy in *****.

My personal experience this year, is that if I hadn't pro-actively requested a PSA test in ***** despite having no symptoms or issues. My cancer would have remained undetected.

My PSA was first tested 'by accident', when i took a private testosterone test and they also tested PSA and advised they couldn't offer testosterone treatment due to high PSA. As a layman, i had no knowledge that testosterone replacement could have increased the aggressiveness of my prostate cancer, and TRT is a treatment being actively promoted to men of my age group.

By this point in ***** , my cancer would have spread outside the prostate capsule, to surrounding tissue and i would have much more complex and potentially terminal situation to deal with.

Post operative histology showed that between biopsy in ***** and Operation in ***** , my 'non-aggressive' cancer had progressed from contained, to breaking the surface of the capsule. My personal experience this year, is that if I hadn't pro-actively requested a PSA test in ***** despite having no symptoms or issues. My cancer would have remained undetected.

My PSA was first tested 'by accident', when i took a private testosterone test and they also tested PSA and advised they couldn't offer testosterone treatment due to high PSA. As a layman, i had no knowledge that testosterone replacement could have increased the aggressiveness of my prostate cancer, and TRT is a treatment being actively promoted to men of my age group.

By this point in ***** , my cancer would have spread outside the prostate capsule, to surrounding tissue and i would have much more complex and potentially terminal situation to deal with.

Post operative histology showed that between biopsy in ***** and Operation in ***** , my 'non-aggressive' cancer had progressed from contained, to breaking the surface of the capsule.

Evidence Comment:

Based on my own experience and talking to friends and colleagues, access to PSA testing is a postcode lottery. Even with familial connection my younger brother (*****) has been refused a PSA test from his GP, despite my Consultant saying he should have one due to higher risk.

A friend in ***** , was told by his GP they didn't do PSA screening – and gave outdated reasons for it (too many false positives etc) – he had to ask two or three times before they treated him appropriately.

This adds to the feeling that the testing for the most common male cancer is random, reliant on the budget management of GPs.

Discussion comment:

I have been fortunate that I progressed through the process quickly from high PSA level. Inconclusive MRI scan. Examination Consultant thought no enlargement of prostate. Biopsy detected early stage cancer cells. Prostatectomy in ***** – so 6 months from initial tests. I have

	no impairment of continence or erectile function after recovery period, almost certainly because my cancer was caught early and treated quickly. It seems obvious to me that a screening programme would mean more men will have similar experience to me. Recommendation comment: Screening should be standardised and recommended. I understand blood tests are more accurate than they were previously (as that is often used as a justification for not standardising) and early detection is key to best health outcome. My experience is strong standards exist to avoid 'over-treatment' eg PSA level for my age group 10 is trigger for further investigation if lower then put under surveillance, if normal no further action taken. Alternatives comment: What are the viable alternatives? Unfortunately, as a layman I am pretty well educated about prostate cancer and nobody has proposed a viable alternative to blood test as a starting point If someone can have prostate cancer progressing with no symptoms, and it is detectable by a blood test – why would you not carry out the blood test for the affected groups – with particular focus on black men, people with familial connection. The reality without screening, is men who are informed of the risks and have access to a helpful GP (or private healthcare) can get the test and those who don't will potentially suffer the consequences. Other comments: I understand the comparison of other countries where PSA screening is carried out have been rejected? Eg Sweden rejected because of different demographics. The demographics are different because the UK has HIGHER percentage of higher risk people, namely black men.
P88	Affected Comment: Not affected, yet Evidence Comment: There would be a loud outcry from women if any of their cancer testing was abandoned due to gender Recommendation comment: Screening saves lives

P89	Affected Comment: I have been affected and the annual psa test saved my life and that of my brother in law
P90	Affected Comment: My friends. Evidence Comment: No. Discussion comment: The recommendation is wrong! Recommendation comment: Screening should be recommended; the upfront cost can be offset by future savings on more expensive treatments, and the UK has more at-risk groups than countries that are undertaking screening. Alternatives comment: I don't know. Other comments: No

P91	Affected Comment: Yes father in law died of metastatic prostate cancer with neuroendocrine features. Died 4 months after diagnosis. He has ***** sons, and they were not given any advice about whether they were at increased risk themselves. Evidence Comment: Views of families Discussion comment: I do not feel the review gave adequate recommendations for men with a family history of prostate cancer, particularly when the disease was an aggressive form. Recommendation comment: I think it should be targeted but to include those with a family history. Alternatives comment: More advice for those with family history – eg sons of someone with prostate cancer. The aggressive nature of father in law's cancer is cause for concern but sons/grandsons have not been given any advice re either genetic testing or PSA monitoring.

Affected Comment:

I am the husband and primary caregiver of a patient diagnosed at age *****. My husband is the exact type of man this policy leaves behind. He is BRCA negative, fit, and had no symptoms. Yet, he was walking around with ***** cancer—an aggressive killer.

Because he didn't fit the "genetic risk" profile you are proposing for screening, he would have been missed. Instead, we have spent the last year fighting for his life. I have watched him endure radical surgery, hormone therapy that broke his bones (*****), and radiation toxicity that hospitalized him for weeks with *****. If a screening program had caught this earlier, the cancer might have been contained, and he wouldn't be living with these life-altering complications.

Evidence Comment:

The review seems obsessed with "overdiagnosis" (treating cancer that won't kill). It completely ignores the evidence of "underdiagnosis" in young, high-risk men like my husband who don't carry a BRCA gene. You are relying on data that suggests only BRCA carriers are high risk. My husband is living proof that this data is flawed. He is BRCA negative, yet his cancer was aggressive and lethal. A policy based on this evidence would have let him die.

Discussion comment:

The recommendation to limit screening to BRCA carriers is dangerous. It effectively tells the public: "If you don't have this specific gene, you are safe." That is false. My husband proved it. By rationing screening to such a tiny group, you are condemning men with sporadic, aggressive cancer to late diagnoses. The conclusion prioritizes saving money on biopsies over saving the lives of young men.

Recommendation comment:

Screening SHOULD be recommended for all men at risk, not just gene carriers. The cost of not screening is not just death—it is the devastation of the treatment required for late-stage cancer. Because my husband's cancer wasn't caught at the "screening" stage, it required "kitchen sink" treatment—surgery, radiation, and hormones. This costs the NHS a fortune and costs the patient their quality of life. Early screening via MRI would allow for less toxic treatment.

Alternatives comment:

If you won't implement full screening, you must mandate "Risk Assessments" at age 45. Currently, men have to fight to be tested. My husband was lucky he had a proactive doctor. Luck should not be a health policy

P93	Affected Comment: A friend Recommendation comment: Yes I think screening should be available to all Alternatives comment: Not sure
P94	Affected Comment: My uncle indirectly died of this disease (he died from Covid, due to immunosuppression) Recommendation comment: The NHS 10 year plan recommends a shift from sickness to prevention. Surely, the decision not to screen for this disease is completely at odds with that plan
P95	Affected Comment: Myself Recommendation comment: I feel that anything that helps detect <i>*any*</i> cancer is a good thing.

Affected Comment:

My father died of prostate cancer and he was failed by the NHS. The NHS was disinterested in prostate cancer and there are underlying systemic reasons for this. Health care discriminates against men and it is more than clear that women's healthcare is funded at the expense of men's health. One only has to look at the comparison between the resources that go into breast cancer compared to prostate cancer. GPs/NHS do everything to avoid helping men with prostate cancer but fall over themselves to everything possible to help women with breast cancer. This was witnessed by our family with my father.

Evidence Comment:

Yes it's an opinion which is heavily influenced by the discrimination against men's health. If this was a condition that affected women, there wouldn't even be a consultation; the screening programme would be in place already.

Discussion comment:

Yes, stop the discrimination and introduce a screening programme.

Recommendation comment:

Should be introduced, too many men are dying due to prostate cancer and there should be equality between men and women's healthcare.

Alternatives comment:

1. Stop the discrimination.
2. Stop looking for excuses not to treat prostate cancer.
3. Stop fobbing men off when symptoms are clear.
4. Introduce penalties on GPs/NHS that fail to act on prostate cancer symptoms and refuse men PSA tests.
5. Equalise the funding for men healthcare and set targets that must be met on prostate cancer diagnosis and treatment.

Other comments:

The Government should investigate the discrimination in healthcare and the culture that persists that men's healthcare is undeserved.

Affected Comment:

Yes, my brother died from late diagnosis and I following slight increasing PSA tests, an inconclusive examination, MRI indicating areas of interest, template biopsy providing Gleason score of 7 and removal of prostate in *****. PSA has been <0.1 ever since. Now annual PSA testing scheduled.

Evidence Comment:

I consider myself lucky. Right place, right time, right postcode and NHS team. I was young at ***** with no symptoms. Your evidence has been interpreted incorrectly. An MRI and template biopsy is definitive and recovery is speedy and it is accurate with respect to understanding the aggressive make up of the cancer. Rectal biopsy procedures should be discouraged to reduce infection risks.

Discussion comment:

Completely disagree with its conclusions. PSA trending, examination, MRI and template biopsy's should be readily available to men.

Recommendation comment:

PSA trending, examination, MRI and template biopsy's should be readily available to men and not be statistically dismissed. Are we as a nation just going to watch men needlessly die? I was refused a BRCA test even with a brother dying of prostate cancer because there wasn't enough evidence – ie I didn't know the history of my parents pathology.

Alternatives comment:

What do you mean by this question – throw money into palliative care? or preferably spend way more on research.

Other comments:

Let Chris Hoy and the cancer charities have a place on the decision making committee.

P98

Affected Comment:

Family – father had prostate cancer. Over-treatment has caused significant side effects

Evidence Comment:

I feel that we missed inequalities. Sweden has fewer ethnic minorities compared to UK, yet still does the screening. Seems foolish to not do this in UK, especially as black men are (I believe) something like twice as likely to have it and die from it.

Discussion comment:

Blood test should be the first move, then send for MRI. Then decide treatment. Aware a lot of men will die of other things before cancer gets them with this disease, and therefore choice enters.

Costs of screening outweigh costs of end of life care and aggressive cancer therapies.

This should be a medical decision, not a political one

Recommendation comment:

Yes it absolutely should. People should be given a choice.

Alternatives comment:

I've worked in the NHS for 24 years. There aren't many alternatives.

This is political speech and a bad question.

They should help by identifying people with the condition early enough to do something about it.

Other comments:

We need to stop looking at decisions that create results in this parliament. Take the politics out of it.

Investment now means people more productive later in life.

Affected Comment:

I was diagnosed aged ***** in *****, but only after being badgered to request a PSA by a good friend ***** who subsequently died a slow, painful death. I discounted HIFU as there was little data on the efficacy, so I opted for active surveillance and subsequently had two MRIs and biopsies. I monitored a gradual increase from ~10 to ~20 then the 2 readings at the end of last year headed off-scale. I elected for non-nerve sparing RALP ***** and am now fully recovered other than ED. If I was having to make the decision (I made in *****) today, I would have elected for HIFU and maybe enjoyed an even better outcome and reduced the three monthly stress of AS, but had it not been for being badgered, I feel certain that I could be looking to a very different future and similar outcome as *****.

The only relevant family history was my mother's sister who had breast cancer and I had absolutely no symptoms that would have made me consult the GP, right up until the operation.

I persuaded my brother (*****) to go back to his GP and insist on a PSA test and he too is now on surveillance.

I have two sons (*****) who WILL be having a PSA before they are 60, no matter what the official guidance is.

Evidence Comment:

Since my own diagnosis, less invasive and less risky treatments (e.g. HIFU) are becoming available and should be considered when formulating the future strategy. Hopefully this will be taken into account by the TRANSFORM study.

Recommendation comment:

If the early indications of the TRANSFORM trial are favourable, then screening should certainly be implemented as early as possible for those at high risk or with family history

P100	Affected Comment: Yes, at least 1 family member and currently, 2 friends. Evidence Comment: From what I've been reading online, I'm convinced that the rejection of screening, based on using the PSA test as a method for early detection of Prostate Cancer, is out of date. Other countries are using a combination of the PSA test, MRI scans, risk stratification and algorithms to use TARGETED SCREENING TO SAVE LIVES. A significant portion of the British population are HIGH RISK eg black men, and need to be screened to help avoid the tragedy of an unnecessary death along with everything that means for their loved ones. Discussion comment: The UK National Screening Committee says that the population of eg Sweden is 'different' than that of the UK – but the essential difference is that there are more high risk men in the UK. The evidence shows that the targeted screening of eg Sweden and other countries is saving lives and reducing the number of cases where it's too late to treat the patients with late stage PC. So the Committee's decision isn't evidenced. Recommendation comment: Screening should be recommended as there is now clear evidence from a number of countries that Targeted Screening is saving lives. The Committee should not ignore this evidence. Early diagnosis also saves money as fewer men will need treatments, hospitalisation, palliative care etc. Alternatives comment: Obviously raising awareness ie education programmes – and changing Government policy so that the NHS is funded to succeed and there are no delays in testing, diagnosis and treatment, but early detection is essential if men are to have a chance of surviving. Other comments: I hope that the committee isn't swayed by the cost of a Targeted Screening Programme- even though it would be more economical, it would require front loading the investment but this would save lives. 9s in power when the credits roll.

P101	Affected Comment: Yes – I have ***** non-family member friends who have been diagnosed with late stage prostate cancer and had radical prostatectomy as a result. I'm aware of other men who have undergone prostatectomy and some who have received a terminal diagnosis in the face of disease that went undiagnosed until cancer was too advanced or had metastasised Evidence Comment: Cannot comment on whether or not any evidence was missed or not suitably emphasised. It appears that the global data available have been considered within this analysis, and one must assume that such data are continually monitored, collected and assembled as the base from which to identify any meaningful trends. Discussion comment: The review materials are clearly presented and should be accessible to every member of the population. Does the team have any measures in play to ascertain how effectively their review penetrates the medical community and population at large? Are these recommendations regarded as guidance or policy? Recommendation comment: It should be a relatively straightforward matter to ascertain those at genuine risk of disease, and prevention should be the goal. What is required however, is highly visible education of the public at large about measures they can take to self-assess and understand the options open to them. The matter of risk/benefit should be an individual choice, and one assumes this choice can be exercised through private healthcare institutions for those who can afford this path. Alternatives comment: 1. National prostate cancer awareness programmes – as regular as those for e.g. breast cancer 2. Mail shots to men every 5 years from the age of 45 containing relevant easy to understand information supporting self-assessment and explaining choices open to them Other comments: A Government-backed funding mechanism to deliver within the next 10 years a reliable, cost-effective screening assay to replace PSA. This could be international in scope. There are almost certain to be cancer-specific markers available in the circulation that can identify potentially aggressive prostate cancers; let's have a NHS initiative to define the state of the art in this space and scope out approaches that can be Government-funded to develop robust assay systems suitable for mass screening

P102	Affected Comment: No this has not affected myself, my family or my friends. Discussion comment: The argument mooted regarding the accuracy of the accuracy of the test doesn't stand up when pitched against the fact that breast screening has much the same issues in testing and potential overtreatment but has been agreed and in place for many years now. Recommendation comment: It should be recommended. The NHS 10 year plan to move towards prevention rather than treatment should advocate screening for a condition that can be treated early relatively cheaply as compared with the cost of late diagnosed treatment options. Investment now for long term savings should be an easy decision. Many extremely rare conditions appear to have been agreed for implementation or in service evaluation by the UKNSC which don't even meet their criteria for introducing a screening programme and are far from cost effective. There is not an infinite pot of money available and conditions such as prostate cancer, which affects many, should be prioritised above extremely rare conditions that affect a handful. Public money spending should always consider a utilitarian approach, too many people are underserved by a struggling NHS that has unrealistic demands put upon it owing to a lack of investment in prevention. This needs to change.

P103

Affected Comment:

This condition has affected my family and specifically my brother. He had no symptoms. Our father died when my brother was ***** yrs and I was ***** yrs old, so don't know if this cancer would have affected him (my father). If a screen had been in place, my brother may have had a chance of beating this disease. He currently has stage ***** with NO symptoms. It has had an enormous impact on his family and his surroundings family.

Evidence Comment:

I don't know about any evidence missed, I just know that this decision is the wrong decision. There are families out there who don't know their family history (adopyed people, fostered people) and they all deserve to have this screening available. Like breast screening. If you took away that screening, just think of the impact on society. These men deserve to have peace of mind and treatment in advance.

Discussion comment:

I just want to say, simply, its the wrong decision.

Recommendation comment:

Yes, I do think screening should be available to every male. Because not everyone knows their heritage.

Alternatives comment:

Psa test for every male between 45 and 65..

Its a no brainer.

Maybe a home test kit, like the bowel cancer test. Surely this could be arranged.

Other comments:

I recommend a different group of people to go over all the evidence.This can not be left to one committee group of people. This is HUGE and a huge decision. I feel strongly they came to the wrong decision.

P104	Affected Comment: Dear Sir or Madam, I disagree with the outdated evidence the committee has looked at. Given that (black) women face similar issues with say ovarian, breast cancers. These are now nationally screened, why not for prostate cancer. Erectile disfunction and dual incontinenace can be managed respctfully with good padding, psychosexual talking therapies and support from incontenance nursing staff. Evidence Comment: The evidence used is outdated as thre is newer in real world published say by Nature medical. Worries of over diagnosis can be mitigated well by pychological talking therapies, some of which nursing staff can be qualified in. PSA testing would not automtically lead to MRI scan or biopsys therefore the diagnostic concerns are not founded, despite government's speech. Discussion comment: No full or draft Equality Impact Assessment has sadly been taken, or contextual analysis compred to female (incl. trans and intersex) person cancers.
P105	Affected Comment: My Dad was unaware he had this cancer, until asked to attend a screening. A good friend also had the same thing. Surely men should be given the same rights to tests as women are for these types of cancer. Especially as there are generally no symptoms until it is too late.
P106	Affected Comment: Prostate cancer affects men with Lynch Syndrome. These men should be included in screening, not just men with BRCA. You need to change your screening to include Lynch Syndrome patients. Failure to do so, will put thousands of men at risk, which inturn will cause premature, needless deaths, as well as the cost of treating them, the economics, time off work, etc. Evidence Comment: Yes, you have not considered Lynch Syndrome men! Discussion comment: Lynch Syndrome should be included. Recommendation comment:

	Yes for ***** with Lynch Syndrome
P107	Affected Comment: Yes – family and friends Mr ***** puts things into perspective ***** Evidence Comment: Important to to exclude the evidence already done that shows targeted screening is beneficial Discussion comment: See *****'s article Recommendation comment: It would seem that the evidence should be directing the UK towards screening Alternatives comment: Throw effective is this alternative (s)? Other comments: None

P108	Affected Comment: Yes.I have ***** friends who have the cancer,screening may have changed the treatment that was needed Evidence Comment: I don't know Discussion comment: The recommendations in the review are not sensible. Recommendation comment: Screening should be used to save men from early deaths and prolonged treatment Alternatives comment: I don't know Other comments: Accept that screening will be productive

P109	Affected Comment: Yes, all of us Evidence Comment: (1) Tellingly, your worries about misdiagnosis include no statistics and no cost-benefit analysis. (2) Men are perfectly capable of deciding for themselves whether and when to undergo treatments. This happens all the time for all sorts of diagnoses. (3) Nothing about how diagnoses and treatments are communicated to patients. In our experience: poorly; inconsistently; confusingly. Universal testing offers the chance to start the conversations early and continuously improve them continuously. (4) No mention of embedding testing for prostate and other cancers in ongoing holistic care for men 50+, so that lifestyle changes go hand-in-hand with long-term preventive medicine, resulting in less suffering for patients and their families, and less cost to the NHS. Discussion comment: See above. Recommendation comment: Yes! See above. Alternatives comment: (1) More pathways with deadlines. The current diagnosis pathway confirms whether or not you have treatable PCa. After that, momentum trickles into the sand while 'multi-disciplinary teams' waste time debating their own view of priorities – which delays treatment by several weeks (2) Most consultants are hopeless at explaining options or even explaining themselves. CPD might help, but it would be more cost-effective to run (downloadable) monthly online video seminars for patient groups, one for each stage of the disease. The current way outpatients is organised wastes everyone's time. And for consultants to offload the emotional workload to barely-trained 'specialist' nurses simply adds to the overall confusion and inefficiency. (3) Some NHS web advice is ok-ish, but most of it dodges the hard questions. This leads to a smorgasbord of well-meaning campaigner sites which suffer many of the same failings. Those that provide forums are more helpful for patients to exchange (largely unmoderated) experiences, but there's an enormous amount of waffle to wade through! (4) The NICE Guidelines were due an update nearly a year ago. What's happened to that? Other comments: Stop being precious about consultants. Too many are stuck in a rut. Motor Vehicle Maintenance gets more attention to process improvement than Patient Pathways. (1) Publish league tables for departments' survival rates and QoL ratings.

	(2) There should be annual in-person departmental peer audits. (3) Enforce CPD and publish compliance. (4) Mandate consultants prepare and share a rolling 3-year Individual Treatment Plan for each patient, with regular check-up dates *and* specific symptom alerts that enable appointments to be brought forward.

Affected Comment:

I was diagnosed with Prostate Cancer in *****. This was following a SERIES OF PSA TESTS over ***** years which begun after I attended a Prostate Cancer Screening event and which showed a steady increase in the PSA level and combined with the fact that there was a family history of prostate cancer. I underwent a physical examination followed by an MRI scan at which *****. This was followed by a biopsy, analysis of which determined I had a quite aggressive cancer. I HAD NO SYMPTOMS WHATSOEVER. There followed extensive consultation in which I was advised of several treatment routes. I chose to have my prostate removed surgically.

Evidence Comment:

Every year many UK men die from Prostate Cancer. Men do not come forward easily, they commonly seek excuses which will keep them away from their doctor. It is not considered 'manly' to have urinary continence issues so many men try to hide the fact that they get up two / three times in the night of have blood in their urine. They grab with both hands the fact that the PSA test is not accurate and use that as an excuse to stay away from any local screening event or their doctor. The evidence presented to the NSC review dwells on the assumption that many tests lead to false positives and false negatives, the outcome of which can be 'unpleasant', 'invasive', 'unnecessary'. However, my own experience and that of many of my contemporaries is that being offered an annual test introduces a balance through the ability to see trends developing. This surely reduces the risk of a false positive or negative, but does not eliminate it entirely. Its all we have at the moment, lets encourage it.

Discussion comment:

Many of the comments in the review dwell on the effects of a 'wrong' outcome of a PSA test, either a false positive or false negative. Its all we have, but it is rarely, if ever, used in isolation. A high reading, or an upward trend, (whether or not associated with other symptoms) leads invariably to further examination, usually a physical examination then an MRI scan which may or may not lead to a biopsy. This is surely a logical process which anyone with suspected prostate cancer should be delighted to be offered. The alternative is 'wait and see' which is not the sort of process I would hope the NHS would wish to be involved in. I read many comments about the 'invasive', 'unpleasant' nature of follow up investigations, but most investigations involving suspected cancer are invasive. They are not pleasant, but the alternatives, i.e. do nothing, are not by any means desirable. A few unpleasant examinations and tests are much more palatable than the many deaths that occur from undiagnosed prostate cancer. False negatives are a different story, but we have no other test available so until we do then we should promote the REGULAR PSA test (i.e. annual) as a MUST for men of 45 or more.

Recommendation comment:

Until we have something else other than the PSA test then I think it is important we conduct screening tests, regularly. At the same time it is important to educate men in the advantages of regular testing, encourage it, show the success that screening events have in identifying potential Prostate cancers, counter the negative arguments against the PSA test whilst not denying the variability in accuracy. At an event in ***** in ***** 102 men came forward for testing, ***** were referred to their GP for follow up. That is potentially ***** men that might have gone about their daily lives for years afterwards unaware of any issues, until it was too late. There may well have been others in that 102 who came away erroneously thinking they were prostate cancer free (because that had a 'false negative result') despite the voluminous information given to them at the event on the subject of false positives and negatives but then they would not

normally have been tested anyway and hopefully they would be in the system and get tested annually thereafter and at least be subject to their GP questions annually.

Alternatives comment:

My own GP was very helpful with respect to understanding the PSA test results. One of my friends is not so lucky. He approached his GP with a request for a PSA test when he found out that his father had died WITH prostate cancer. His GP just asked him if he had any symptoms, to which the answer was "no". So the advice was "go away and if you experience any symptoms like urinary issue or blood in your urine come back". I MIGHT NOT BE HERE TODAY IF THAT HAD BEEN THE ADVICE I HAD RECEIVED FORM MY GP. I believe that until a more efficient and effective tool is available we should use the PSA test and any patient over 45 should be automatically given a test annually and instructed in the pro's and con's of the test and alternative follow up investigations.

P111	Affected Comment: I know a of ***** friends who have prostate cancer *****. Evidence Comment: Many men are dying from this surely this is enough evidence. Discussion comment: I personally think that there is not enough being done to tackle prostate cancer. I believe it is one of the biggest scandals of our time. Men are being discriminated against. There is national breast cancer and cervical cancer screening process in place for women. Recommendation comment: Yes too many men are dying from this disease. Alternatives comment: No there needs to be a screening programme. Other comments: Government needs to fund significant research into prostate cancer screening.

P112	Affected Comment: I have prostate cancer and am undergoing treatment. It was caught sufficiently early and I will survive. My ***** also has prostate cancer. Discussion comment: I find it remarkable that other countries with a lower risk populations are conducting targeted screening that is proving effective by increasing early diagnosis and decreasing mortality and the related long-term and palliative care requirements and this evidence is not driving a similar system in the UK. The savings in time, money and lives should be obvious and I have not read any credible counter to this evidence in the review. Recommendation comment: I requested a PSA test when my ***** was diagnosed which produced a negative result. Ever since – understanding that I am at a higher risk – I have been aware of the signs and symptoms. Therefore, when I began to experience symptoms I attended my GP and presented my concerns. It was because of my risk factors and awareness that I pushed for a PSA that led to an MRI, examination, biopsy and diagnosis. Has I not 'self-screened' my cancer would now be developing unchecked as I have very minor symptoms. Alternatives comment: If we are not to actively screen then we must at least make vulnerable men mor aware so that they can self-screen to some extent. Target those that are vulnerable with information and make GPs aware and receptive. Other comments: More work is required on this subject. Greater gathering of evidence and more scrutiny. Screening is not always the right solution but with a hierarchy of tests available from PSA, GP exam, Consultant exam, MRI then biopsy there is an escalation of non-invasive tests that will confirm the presence of cancer or not. These tests are simple and painless (less biopsy!) and save lives. Mine included, Do that.

P113	Affected Comment: Friends affected Evidence Comment: why were no representatives from high risk ethnicity represented on the panel? Discussion comment: why were no representatives from high risk ethnicity represented on the panel? Recommendation comment: Screening should be offered. It is important to offer men the same support women receive for breast cancer and cervical cancer. Alternatives comment: education about symptoms is helpful but a screening programme is the top priority Other comments: screen, screen, screen!
P114	Affected Comment: I live in a small village ***** Out of ***** households ***** households are dealing with late stage prostate cancer – all ***** males, all over *****. The cost in human and economic terms is considerable. I would urge the Government to reconsider. Evidence Comment: I think that there is a potential for mis – calculations on incidence Discussion comment: Please consider the human cost. Recommendation comment: The risks are very low – look at Swedens policy Alternatives comment: I don't agree there are alternatives

P115	Affected Comment: The condition does not currently affect my family but has affected friends Evidence Comment: The decision does appear to be not in line with that taken in other countries Discussion comment: Surely if there is evidence that risk stratified processes works well in other countries we should be doing this Recommendation comment: Risk stratified processes are and have worked well in the condition and have had a positive impact on preventing deaths
P116	Affected Comment: Yes it has affected me greatly. My GP told me over a multi year period that my PSA level was within guidelines and I did not need to be referred. After several years I did my own research. My PSA was ***** for urgent referral to a Urologist. I asked my GP for a referral. They refused until *****. At this point the GP became indignant, saying it was not necessary. The GP did however finally refer me when I made it clear I would not back down. I was seen by the Urology dept at my local hospital very quickly after my notes were sent to them. I had various tests over the following weeks and was told I had ***** prostate cancer and my only option was surgery asap. I was told that the GP should have referred me some years before when I would have had other less invasive options instead of surgery. This was nearly ***** years ago. I have just been diagnosed with recurrent prostate cancer. Had my GP done their job properly and referred me ***** earlier I may not be in the situation I'm now in. GPs are not qualified to judge on specific medical issues. They are General Practitioners, not specialists. The GPs I saw do not believe in the PSA test saying it's unreliable and not to be believed.

	For this reason the testing needs to be taken out of the GPs hands and give to specialists via a national screening programme. The staff at the Urology department that I saw all said the same, that they hear my story over and over again. Where is the harm – physically or emotionally – in having a national screening program that uses the PSA test and then MRI scans. I admit the biopsy is not a pleasant experience, but neither is it dreadful, and if you're at the biopsy stage, you will have had PSA tests and MRI scans so you've probably got cancer that probably needs to be dealt with. After some years and many, many letters / emails giving evidence of the failure of my GPs to the senior GP at the practice, they finally reviewed my case, admitted their failure and gave me an apology for not referring me much sooner. We need a national screening program so more men don't go through the awful experience I have had at the hands of the GP practice I'm with. Evidence Comment: See above. Discussion comment: We need an independent screening program. We also need a completely unbiased independent investigation into how the review came to the conclusion that a national screening program was not required. The money that could be saved from a national screening programme and early detection would no doubt pay for itself many times over. Recommendation comment: Yes it should be recommended for the reasons stated above. GPs are not qualified to asses for cancers etc, they are GENERAL PRACTITIONERS. Most GPs I have come in contact with do not believe in the PSA test. Alternatives comment: Start with a national screening program – PSA testing followed by MRI scanning, then biopsy if necessary. Other comments: Start an independent screening program immediately. Take it out of the hands of GPs.

P117	Affected Comment: My father is diagnosed with prostate cancer Evidence Comment: Targeted screening will reduce the risk to at risk people and should be progressed as a matter of urgency. It will cost in advance but save money and lives in the long term Discussion comment: Targeted screening will reduce the risk to at risk people and should be progressed as a matter of urgency Recommendation comment: Yes. Targeted screening will reduce the risk to at risk people and should be progressed as a matter of urgency. It will cost in advance but save money and lives in the long term
P118	Affected Comment: If a close relative had not had a routine test he would not have discovered he had prostate cancers...it is a dangerous and irresponsible to not continue with this service. Evidence Comment: None Discussion comment: Recommendation don't change what's not broken !

P119	Affected Comment: Yes a friend who is a black male died from prostate cancer. This has had a devastating impact on his wife, children, friends. and wider community that knows him. His sons are now at a higher risk of this cancer. Evidence Comment: I think the evidence is clear that black men are disproportionately impacted as well as those with a family history. There needs to be screening for this group. It concerns me particularly that yet again people of colour/certain ethnic groups are negatively impacted by the healthcare provided and are not often considered appropriately with regards screening and healthcare. There is a clear systemic issue that keeps occurring. Discussion comment: The review can change it to from mass screening to those at higher risk. The uncertainty in the data is not a reason to not include the group. The evidence is showing this group is at a higher risk. A targeted approach can clarify the data, that is better than letting people die. Recommendation comment: Screening should be recommended to also include for black men who are disproportionately impacted as well as those with a family history. This group often has poorer health outcomes. Even if this group is added for screening the evidence already shows that those who need the screening do not always attend for screening, let alone go to their GP for advice. This targeted approach will at least catch some who need it. This outweighs the risk from the evidence shows this group are more likely to die because they rarely seek medical advice. Alternatives comment: I endorse screening for the groups stated, but of course more information, promoting advice is helpful. The problem is with this condition the symptoms occur later in the stage of the condition when medical intervention is often too late. Other comments: Include the groups of black men and those with a family history. Trial it and see if there is a difference. It is so concerning that we know ethnic groups have poorer outcomes in healthcare, and something that could address this in this area is not being included. We must stop ignoring the signs of institutional and systemic discriminatory processes.

P120	Affected Comment: Yes, both friends and family. Lack of any type of formalised screening contributed to the severity and need for extensive treatment of the cancer. Had screening been conducted the life expectancy and ongoing trauma would have been much reduced. Evidence Comment: Ignoring other countries operations and experience is a fundamental flaw in the approach. We have a higher risk population and no screening. Discussion comment: Recommendations continue to put a significant proportion of the population at risk. Recommendation comment: Screening should be recommended. Even if there is some relatively minor harms through screening, the absence of screening contributes significantly to harm and male mortality across all populations. Alternatives comment: Increased national information and education programmes in conjunction with screening. Other comments: As above
P121	Affected Comment: Prostate cancer has affected a significant number of my immediate family and friends. Caught early we know the outcomes are very positive for those diagnosed early. The fact is though that too many are caught too late resulting in significant costs to the healthcare system. It is unthinkable that we in an advanced society with the benefits of a universal health system are outliers in screening for this disease as a matter of course. Recommendation comment: Screening absolutely should be recommended. What is the NHS for if it is not to protect the health of our population.

P122

Affected Comment:

I have prostate cancer as did my father. A disproportionate number of my friends have prostate cancer. Of ***** friends with prostate cancer ***** were missed and only diagnosed at stage 4. The other ***** have been treated with limited side effects. I have been under "watch and Wait" for two years and will be having a two year phone call ***** with only a Psa check done for the review. (is that sufficient?)

Evidence Comment:

You are confusing the need for diagnosis with treatment options.

The evidence that you give for not undertaking screening is based on any resultant treatment not for the screening process itself.

The entire report is incorrect and does not give any concrete evidence as the why screening should not be undertaken

There are no reasons for not undertaking a Psa test followed by a physical examination followed by an mri followed by a biopsy. On that journey the only procedure that has any minuscule risk is the biopsy and for 99.9% any issue is temporary.

Discussion comment:

See the text in the above comments box.

The review is completely mixed up and as a result the conclusions are unsupported and incorrect.

The review has associated the risks when TREATING prostate cancer with NO RISKS when DIAGNOSING prostate cancer and used these as the reasons for not supporting a screening programme

It's quite clear that a screening process is urgently required, that it will save countless lives, and that other than the costs, there are no risk or psychological reasons as to why it shouldn't be set up

Recommendation comment:

See above two boxes.

Yes the screening process should be set up urgently

Alternatives comment:

I cannot think of any alternative to physical screening. Your comment is misleading.

Setting up a screening programme requiring men to pay for part of the screening process or getting companies to offer health checks or gymnasiums to offer tests, to run road shows with bloods tests in high streets stations etc

Other comments:

	Screening needs to be put in place urgently. The report has not given any reason why this should not happen
P123	Affected Comment: I have a moderately high PSA and am adopting a watch & wait strategy. My ***** underwent radical prostatectomy following a raised PSA at a time when he was asymptomatic. His subsequent life has been blighted by urinary frequency, urgency and incontinence. He survives, but has a very poor quality of life due to advanced ***** (onset about 2 years post surgery). Did he sacrifice 2+ years of good QOL to gain increased longevity into a period of terminal decline? Perhaps he gained nothing! Discussion comment: Well done! Recommendation comment: Not at present, based on the evidence available. Other comments: A future decision should be solely evidence-based. Political pressure should be ignored. Why should my treatment be decided by emotive mob hysteria?

P124	Affected Comment: My husband was diagnosed with stage 3 prostate cancer in *****. He had no symptoms. This only came to light at this time because ***** had been recently diagnosed with prostate cancer and urged my husband to get himself checked. Had he not, he would have been non the wiser until this cancer was stage 4 and untreatable. It makes no sense at all to deny men routine screening. It will save the lives of men walking around with a cancer they do not know they have. Recommendation comment: Routine screening should and must be recommended!
P125	Affected Comment: A friend was diagnosed only after his doctor ask if he would like a routine screening Evidence Comment: If it wasn't for the proactive test a more serious condition would have developed Recommendation comment: Yes, I would think the lower cost of screening would be financially better that curing an inverter developed cancer Alternatives comment: Combine the test with existing blood tests
P126	Affected Comment: It's affected a number of family and friends Recommendation comment: Should be recommended – it's a significant killer of males, we screen for bowel, breast, etc cancers and the argument not to screen for prostate cancer is insufficient

Affected Comment:

My father died of Prostate Cancer at ***** years old, having only being diagnosed 2.5 years prior. Leaving a wife, *****. He didn't smoke, he didn't drink and played ***** until he was ***** years old. We were seeking a test for 'sleep apnea', as he kept falling asleep and the suite of bloods taken to start reviewing this, highlighted an extremely high PSA score. It turns out, he'd had problems passing urine for several years prior, but didn't seek help from the GP. When we eventually saw the consultant, my father was 'clinically diagnosed', as it had breached the prostate. We weren't offered chemo, only injectable hormone drugs. My brother is now ***** years old and as a family don't want him to experience this dreadful disease. We aren't aware whether he has BRCA1 or BRCA2 genetic mutation, as none of us were offered any further testing when dad passed away. I'd like to see him and others be given the opportunity to have their genetics tested, to see if they are pre-disposed, if the PSA test appears to be so unreliable. All I know is that we only had ***** weeks between dad feeling relatively well and then being on a syringe-driver for ***** days before his passing. My dad passed *****.

Another of my ***** proactively started to monitor his symptoms shortly after dad died, *****. He was diagnosed with an enlarged prostate initially, this within ***** years developed in to prostate cancer and he decided to have his prostate removed *****. He is fit and well and importantly still alive.

Another of my ***** also had prostate symptoms in his ***** , he went for testing and was struggling to pass urine. he has had surgery to remove part of his enlarged prostate and remains under supervision.

It doesn't get any easier. Within the last two weeks, we have also said goodbye to another of ***** , who was also diagnosed circa ***** year old and died in his ***** year. He too has left ***** . Another family left devastated.

Please allow genetic testing for BRCA1/2 if we are ever to get ahead of this disease and many others, rather than playing the 'wait and see', which is often too late.

thank you for reading.

Evidence Comment:

i think there should be a costing exercise undertaken in relation to the mass genetic testing of the population, to help identify the potential for this cancer and many others. no costings it appeared where considered, versus the cost of multiple scans, hospital visits, drugs, gp time, consultant time etc.

Discussion comment:

Whilst the recommendation to offer 2 year testing to those with BRCA1/2 mutations is admirable, many of us haven't been genetically tested, so will not benefit from this recommendation, until perhaps it's too late again. Testing families of those who have passed from a cancerous disease will help to pro-actively monitor the health of the population, rather than reacting to symptoms (if they have any symptoms).

Recommendation comment:

I think genetic screening should be recommended, to highlight those who are at greater risk of developing the disease and giving the patients an option of how they wish their care to be planned, rather than having no choice, as in our case.

Alternatives comment:

Clearer social media, highlighting early symptoms, encouraging men to attend for their health checks and long term conditions reviews. Provide support to the families who are left behind devastated, not knowing which way to turn.

Other comments:

Please fast-track this initiative, without sacrificing the validity of the research.

P128

Affected Comment:

My brother has had Prostate cancer and underwent weeks of gruelling radiotherapy. I would hope that his son, now aged ***** would be screened for this condition. He is the only close male relative.

Fortunately my brother is still alive but still has regular check ups for the condition. He lives in ***** so not sure if the rules are different there.

Evidence Comment:

It seems to me dismissed some of the evidence from Scandinavia as the countries are different. However although more common in black men you only have to look at Chris Hoy and Joe Biden that it affects people of all ages and indeed people who are very fit as well as elderly.

Discussion comment:

I think the conclusion not to go ahead with screening was really based on cost of a screening programme. I think the examples in Scandinavia show that it can significantly reduce the number of serious cases requiring major input from healthcare. Not only the savings that will be made there but also possible other welfare benefits such as PIP or Attendance allowance as well as reduced taxes because no longer able to work are all costs to society. However the cost to the patient and their close family and friends is incalculable. Not only the pain and suffering but the worry about the spread and what happens in the future.

Recommendation comment:

I think at least targeted screening should be introduced. With the ability to do MRI scans for any that initially look to be of concern there will be little harm done during the process and a lot of potential benefit.

Alternatives comment:

There could in addition be publicity campaign about the symptoms so that those not initially targeted will be encouraged to come forward to get checked earlier rather than later.

P129	Affected Comment: Yes, in that my father died prematurely of prostate cancer, and I have been given multiple annual PSA tests, following a raised result a few years ago. I was then about to have a biopsy, but instead was offered a MRI scan, which showed only minor suspicious changes. Subsequently, I was diagnosed with *****, and I'm receiving treatment for that condition, with little effect Evidence Comment: There seems to have been a trend to avoid biopsies, for which I'm grateful, but this doesn't appear to have been recognised. Perhaps the practice is not sufficiently widespread, and I was just lucky not have been subjected to a biopsy. The combination of PSA/MRI is possibly already sufficiently accurate to be worth implementing now, without having to await results from the Transform trial. Discussion comment: The review appears to have given little regard to the overwhelming public pressure and political/celebrity endorsement for screening. That position is reasonable and justified, but will have to be spelt out much more clearly if the recommendation were to be accepted by Ministers. Recommendation comment: Whole population screening is not yet desirable, but high risk groups, as identified in the review – black men and those with a family history – should be offered screening now. The very small group of those men with a genetic predisposition is an unsatisfactory intermediate step. Alternatives comment: As an alternative to biopsies, a more accurate blood test – with fewer false positives and negatives should be developed, and that should be offered to men over 50 as the first step, rather than having to be requested. Other comments: The balance of risk between under and over diagnosing should be more clearly explained, and the possibility of both these being reduced.
P130	Affected Comment: Getting testing follow ups was already too difficult – this wont help Recommendation comment: it should be yes

P131	Affected Comment: Many friends Evidence Comment: The evidence is out dated. Discussion comment: Screening should be available at least to the most vulnerable groups Recommendation comment: Recommended Alternatives comment: Routine bloods Other comments: No

P132	Affected Comment: My father was affected. Many of my friends husbands have been 'caught' by chance some not so lucky which makes it a lottery without a screening programme. Evidence Comment: Don't do biopsy routinely just blood test and MRI if needed. Discussion comment: Recommendation is wrong. Recommendation comment: There should be routine screening I worry for my sons.
P133	The recent recommendations about not screening for prostate cancer seems to me to be fundamentally flawed. My own experience of not getting screened and not having many symptoms that would have indicated a need to be screened, would have been different had standard screening been done. I was only diagnosed because I had a blood test for a medical and that's what began the process of getting diagnosed and treated. The decision to not screen will miss many men who are in a similar position to me. I hope that this decision can be changed.

P134

Affected Comment:

My husband, due to our vigilant GP, was sent for testing and as a result had a radical prostatectomy. It saved his life. He was complaining of increased micturition at night.

We did not know that both his ***** and ***** had died with prostate cancer. When warning other relatives we were told about these close relatives. They were not a family to ' discuss such things' we were told – almost ashamed of the diagnosis or embarrassed to mention it.

Evidence Comment:

I know of women very upset by their false breast screening result and assume these cases and their cost have influenced the committee. I think these ideas are out of date and irrelevant today. Who sits on such deciding committees? Are they fully representative of the opinions held by all men in today's UK? Are they fully aware of black and asian men's increased incidence of Prostate cancer and their death rate?

Discussion comment:

This is so important I think the decision should be reversed or at least reconsidered.

Recommendation comment:

It should certainly be reconsidered by a committee fully representing the ethnicity of all our population and the top current surgeons practising in this field. Look at what careless choice of so called experts has done in the Paediatric Nurse Letby's case – still not rectified.

Alternatives comment:

Stop endless committee considerations.Be brave and act to save lives now.

Other comments:

Stop wasting money on endless, unnecessary changes to our NHS. Restore it to the original Bevan principles and throw out endless US think tanks advising with £signs not patient outcomes in their minds.

Affected Comment:

My husband diagnosed with prostate cancer.

Evidence Comment:

They are not taking into account other countries data.

Discussion comment:

Survival depends on catching it before prostate cancer slips into your life.

Roughly half of prostate cancers are diagnosed by chance.

The other half present with symptoms, often at a more advanced and dangerous stage... and too late. My husband had symptoms and a slightly raised PSA. He had a MRI scan at some point. They couldn't get a biopsy without anaesthetic so said they would wait to see if the PSA raised further. Which it did, and they did a biopsy with anaesthetic. Then diagnosed with prostate cancer. The cancer was there at the first PSA test. Thank god I told him to chase up getting the second PSA test.

In other words, without organised screening, men are left to rely on luck.

I cannot believe The UK National Screening Committee has said 'no', to targeted screening even for the men most at risk...black men and those with a family history. My husband didn't have his father's family history. He never knew him. Following DNA testing on ancestry ****. This was after PSA testing.

The UK national screening predecessor committees have said no since 1997.

It's hard to see how this latest conclusion is right.

The Committee's first line of argument is that prostate cancer screening risks 'overdiagnosis' and 'overtreatment.' An argument that is old hat.

Modern risk-based approaches... don't biopsy everyone with a raised PSA... they're MRI'd, risk-stratified and the majority left alone.

Sweden, Norway, parts of Germany are doing this. Their data shows what ours would show... target-screen fewer men 'unnecessarily', catch more cancers, treat fewer late-stage cases.

Mike Richards chairs the screening committee, eleven people, eight women and no black men?), that dismisses lessons from Sweden.

Apparently, the population there in Sweden is 'too different'... code for fewer minority ethnic groups. The very groups that make England different are the groups at higher risk... black men who have roughly double the incidence and double the mortality.

If Sweden can justify targeted screening with a lower-risk population, how can England justify refusing it in a higher-risk one?

Treatment for advanced disease includes long-term hormone therapy, repeated imaging, radiotherapy, chemotherapy, palliative interventions, end-of-life care.

	Early, curative treatment means fewer men requiring complex combinations of drugs and the spiralling costs of modern oncology. Family history is vital. In medical terms, family history is well accepted as; ‘... first-degree relatives (father, brother, son) with a diagnosis of prostate cancer, sometimes extending to second-degree relatives, grandfathers. Risk calculators, guidelines, international screening protocols, Sweden, the US, and NICE, rely on this family definition. No ambiguity. Science increasingly favours risk-based screening. Everything we need; PSA, MRI, risk-stratification algorithms... all exist. Screening saves lives. The decision to not screen is morally wrong and putting men at risk. Is the government willing to put lives at risk? Well obviously they are with the current position of not screening. Recommendation comment: Screening should be recommended. Other comments: Follow other European countries where they are screening.

P136	Affected Comment: I was diagnosed and treated for prostate cancer in *****. Evidence Comment: To what degree was cost considered? I suspect that cost and lack of staff and equipment were in reality the main drivers in the conclusions reached. I was treated privately but even so, the wait for a biopsy was long. The first comment from the private urologist was that even the private sector was inundated and struggling to cope. So your contention that a PSA test is unreliable and therefore the main reason for not having a screening program is bogus. Why is PSA testing post treatment the main monitoring tool if it's unreliable? Discussion comment: See above. Recommendation comment: Definitely should be recommended. Mine was found in a general health check and was already advanced despite the lack of symptoms. A screening program would have picked it up at a much earlier stage and the treatment would have been easier and cheaper. Alternatives comment: Rubbish! You're looking for cheapskate solutions which will cost thousands of lives. Bite the bullet and invest properly in our health. It's mainly older men who are affected by this and we have already paid a fortune in tax and NI. It's time for a return on our investment. Or don't older men and in particular older black men matter? Other comments: Introduce the very necessary screening program for men at age 60 onwards at the latest and at age 50 if there is a history of prostate cancer in the family. If need be introduce a small post retirement NI contribution to offset costs. But don't pretend this will be sorted magically by not having a decent screening system. If the French can do it effectively, so can we. Get your fingers out and invest properly in the nation's health and stop trying to con the nation into thinking it's not really a financial issue. After all you're not the Tories!

Affected Comment:

My ***** had, but did not die of prostate cancer. My ***** is being treated for an enlarged prostate. Two years ago I was identified as having a slightly enlarged prostate. When I has symptoms, I was seen by my GP within a week, and with the next to weeks, had received a physical exam, a CT scan and an MRI which thankfully, confirmed I did not have prostate cancer. However I will now be regularly monitored.

Evidence Comment:

Using a modern risk-based approach, you don't need to biopsy everyone with a raised PSA. Use MRI and risk-stratified and you'll find the majority are left alone

Sweden, Norway and parts of Germany are doing this. Their data shows what ours would show: target-screen fewer men 'unnecessarily', catch more cancers, treat fewer late-stage cases.

The committee comprised eleven people: eight women and no black men – hardly a reflection of our population

Apparently, the population in Sweden is too different, i.e. fewer minority ethnic groups. So why is it the very groups that make England different are the groups at higher risk, black men who have roughly double the incidence and double the mortality.

If Sweden can justify targeted screening with a lower-risk population, how can England justify refusing it in a higher-risk one?

Discussion comment:

Treatment for advanced disease includes long-term hormone therapy, repeated imaging, radiotherapy, chemotherapy, palliative interventions, end-of-life care.

Early, curative treatment means fewer men requiring complex combinations of drugs and the spiraling costs of modern oncology.

Recommendation comment:

Targeted testing could catch prostate cancer earlier and reduce long terms impacts.

Risk calculators, guidelines, international screening protocols, Sweden, the US, and NICE, rely on the family definition with no ambiguity.

A targeted screening program mirroring the risk-stratified approach used in Sweden, might cost ~£225 million annually.

It's a lot but, cut late-stage presentations by even 20% (and the evidence is, it would be exceed that) the savings in avoided late-stage treatment and end-of-life care are also, a lot.

Alternatives comment:

No – screening shifts spending forward and prevention requires money now. Savings that will arrive after this current Government is gone.

Science increasingly favours risk-based screening. Everything we need; PSA, MRI, risk-stratification algorithms... all exist.

Screening saves lives but if it can't be shown to save money by next week, the system finds a way to say no.

Other comments:

The Secretary of State for Health needs to re-consider the findings of the committee and implement a screening program.

Affected Comment:

My husband was diagnosed with prostate cancer in his *****. He's a ***** so knew what to ask for at the GP. However initially the GP declined him a PSA test as he had no symptoms.

Because he was a ***** he kept asking and so was finally given a PSA-which was slightly raised. Nothing to worry about said the GP. He persisted and was referred into his own team. Who subsequently did an MRI which found quite significant prostate cancer.

He had surgery which couldn't spare the nerves sadly as it was found to have advanced too far.

Luckily he is well, despite the obvious problems that surgery can leave people with. But he's alive and ***** years have gone by-each one a worry when the test comes round again.

We need screening because:

1. Many GPs avoid doing PSAs.
2. Too many men with low PSAs aren't referred as they should be.
3. The most vulnerable people in our society aren't at their GPs and may not push like my husband could as he was armed with facts and experience. They won't get testing done early enough to give them good outcomes if they have the disease.

Discussion comment:

It's complete madness not to introduce screening for men. As woman I'm fortunate to have access for a range of screening that could potentially identify cancer earlier and this is inequitable.

Recommendation comment:

It should be recommended as it will save lives, it will diagnose cancers earlier so men have better outcomes.

Alternatives comment:

Men currently who have the condition have zero access to psychological support. this is a travesty considering the impact of the treatments.

Other comments:

Get on with implementing the screening programme.

Improve the terrible current waiting lists for treatment.

P139

Affected Comment:

I have had prostate cancer.

I had no symptoms, had a raised PSA, followed by MRI scan, biopsy and positive diagnosis. Treated with radiotherapy and hormone therapy. Now thankfully successful.

Evidence Comment:

Yes, there is a point which has been missed...

My treatment had side effects, none of which were pleasant. However, I could cope with most side effects.

What is missing from consideration is this... Like many others, I would rather live with the after effects of treatment than carry on without knowing that I have cancer, or that it has reached the stage where it could be terminal.

Discussion comment:

The figures are open to various degrees of interpretation. Figures are meaningless: it is people who are important. Anyone should be allowed, or invited to have, a screening test. Being diagnosed is terrifying, but better to know, and be treated, than to carry on in ignorance of a cancer in your body.

Recommendation comment:

It should most definitely be recommended.

If I had not been tested and treated I could well be dead by now.

Alternatives comment:

There will always be new treatments and methods of diagnosis coming into use. Keep researching these improvements.

Other comments:

Yes.

Listen to the views of ordinary people, and those who have been through prostate treatment.

Listen to those charities who work brilliantly to progress research, help those who are going through treatment, and support them after they have received treatment. They know the day-to-day experiences of those who have been affected.

Affected Comment:

I was diagnosed aged ***** in ***** by chance. I has localised peripheral Gleason score *****.

Thanks to the NHS, ***** charity, ***** and the team at *****, I was treated in ***** with High Intensity Focussed Ultrasound (HIFU). My PSA levels are acceptably low and the chances of recurrence are only 5% greater than traditional methods of treatment. My lifestyle has been preserved and I do not suffer the outcomes associated with traditional treatments.

Evidence Comment:

I am very surprised there is no mention of any focal therapies including HIFU (High Intensity Focussed Ultrasound) and Cryotherapy. These are cost-effective effective treatments methods with only a 5% difference in recurrence to the more traditional radical interventions such as Radical Prostatectomy, chemo and hormone therapies.

The UK NSC's recommendation against population screening is heavily weighted by concerns about overdiagnosis and overtreatment harms. However, the economic model appears to assume that all diagnosed cancers lead to either:

Active surveillance (with associated anxiety)

Radical treatment (with significant side effects)

The documents note that radical treatments cause substantial lifelong harms including urinary incontinence (19% moderate-to-severe after surgery), erectile dysfunction (50-66% after surgery or radiotherapy), and bowel problems.

Why Focal Therapies Change the Equation

1. Reduced Treatment Morbidity

Focal therapies like HIFU and cryotherapy target only the cancerous tissue rather than the entire prostate, potentially offering:

Significantly lower rates of incontinence and erectile dysfunction

Outpatient procedures with faster recovery

Preservation of quality of life

Offer a middle ground between active surveillance and radical treatment

The SCHARR model's conclusion that screening for all men "may well do more harm than good" and results in "substantial overdiagnosis" is based on treatment pathways that don't include focal therapies.

If the model incorporated focal therapy for Grade Group 1-2 disease, the harm-benefit calculation would shift because:

Reduced disutilities: The utility decrements used in the model would be lower for focal therapy patients

	Lower treatment costs: Focal therapies are typically less expensive than radical surgery or radiotherapy courses Reduced overtreatment burden: Men with low-to-intermediate risk disease could receive proportionate treatment The model acknowledges that “around 40-50% of prostate cancer cases detected by PSA screening will be slow growing”. For these cases, focal therapy represents a clinically appropriate middle pathway. Revised Screening Proposal A national screening programme for men over 50 could be cost-effective if it included: Risk-stratified screening with PSA + mpMRI Treatment algorithms that match aggressiveness: GG1: Active surveillance GG2: Focal therapy (HIFU/cryotherapy) as first-line GG3+: Radical treatment or focal therapy with close monitoring Patient choice with full information about: The option to avoid radical treatment harms The trade-offs between focal and radical approaches The possibility of salvage treatment if needed Discussion comment: The NSC should identify and analyse the benefits of focal therapies. To make such an important recommendation without the cost and health benefits of focal therapies is a major oversight. The NSC documents appropriately identify data limitations. A revised model incorporating focal therapies would need: Long-term oncological outcomes for focal therapy in GG2 disease Quality of life data comparing focal vs radical vs active surveillance Cost-effectiveness analysis including focal therapy pathways Uptake estimates for focal therapy options The current recommendation against population screening is based on a false dichotomy between overdiagnosis through active surveillance and overtreatment through radical therapy. The conclusion that “whole-population screening may well do more harm than good” does not account for focal therapy options that could dramatically reduce treatment-related harms while still providing cancer control.

	A national screening programme that incorporates focal therapies for appropriate Grade Group 2 cases would likely demonstrate: Improved net monetary benefit Reduced treatment-related disutility Lower overtreatment rates Better patient acceptability More proportionate use of healthcare resources The NSC should commission modeling work that includes focal therapies in the treatment pathway before making a final determination on population screening. Recommendation comment: Screening should be recommended. The UK NSC's recommendation against population screening rests heavily on the harms of overtreatment. However, their economic model contains a critical omission: focal therapies like HIFU and cryotherapy are never mentioned. This represents a false choice between doing nothing (active surveillance with anxiety) or doing too much (radical surgery/radiotherapy with lifelong side effects). The NSC documents acknowledge that 40-50% of screen-detected cancers are slow-growing, leading to "substantial overdiagnosis." For Grade Group 2 cancers (47% of detected cases), the model assumes patients face either: Active surveillance with psychological burden Radical treatment with 19% severe incontinence, 50-66% erectile dysfunction, and significant bowel problems Focal therapy offers a third way: treating only the cancerous tissue, dramatically reducing side effects while providing definitive cancer control. The model's conclusion that screening causes "more harm than good" is based on outdated treatment paradigms. When 61% of GG1 patients on active surveillance eventually switch to radical treatment within 15 years—often due to anxiety rather than progression—we're not avoiding overtreatment, merely delaying it. For GG2 disease specifically, focal therapy: Addresses cancer definitively, eliminating surveillance anxiety Preserves quality of life with minimal incontinence/erectile dysfunction Costs less than radical treatment courses Allows salvage radical treatment if needed Cost-Effectiveness Reconsidered

The SCHARR model predicts screening men aged 58-60 has marginal positive net monetary benefit (£17) with 49% overdiagnosis. But this assumes all treated men receive radical therapy with its associated:

- High treatment costs (£2,482-£6,047 first year)
- Significant utility decrements (multipliers of 0.83-0.96)
- Lifelong surveillance costs

Incorporating focal therapy for GG1-2 disease would:

- Reduce costs: Outpatient procedures vs. radical surgery/radiotherapy
- Improve utilities: Minimal side effects mean smaller quality-of-life decrements
- Lower perceived overtreatment: Proportionate treatment matches disease severity

The model shows single screening at age 60 saves 240 lives across 395,660 invited men over 15 years. Currently, those lives are “saved” at the expense of substantial overtreatment harms.

With focal therapy, the benefit-harm ratio fundamentally shifts.

A Modern Screening Programme

A 21st-century screening programme should offer:

- PSA + mpMRI screening for men 55-65
- Stratified treatment pathways:
 - GG1: Active surveillance
 - GG2: Focal therapy first-line
 - GG3+: Radical treatment
- Patient choice with transparent discussions of trade-offs

The NSC asks whether screening does “more good than harm at reasonable cost.” By excluding focal therapies, they’ve answered a different question: whether screening followed by 1990s-era treatment protocols is cost-effective.

Modern focal therapies transform overtreatment from an inevitable harm into a manageable risk. The NSC should commission modeling that includes these options before concluding that screening an entire generation of men offers insufficient benefit.

Without considering focal therapy, the recommendation against screening is based on incomplete evidence.

Alternatives comment:

The TRANSFORM trial (Prof. Hashim Ahmed – lead) is an excellent trial but we cannot wait for several years for the results.

Prostate cancer remains one of the most prevalent malignancies among men, yet its biological behaviour is highly variable. A substantial proportion of men diagnosed with localised, low- to favourable-intermediate-risk disease—particularly those with Gleason Grade Group 2—face a challenging dilemma: proceed with whole-gland treatments that carry significant risks of long-term side effects, or choose active surveillance and live with uncertainty. Focal therapy provides a compelling, evidence-supported alternative that deserves rapid and widespread deployment within modern prostate cancer care pathways.

Focal therapies—such as High-Intensity Focused Ultrasound (HIFU), cryotherapy, irreversible electroporation (IRE), and focal laser ablation—target only the cancerous region of the prostate while sparing surrounding tissue. This approach mirrors successful organ-preservation strategies in breast, kidney, and liver cancers. The principle is simple: treat the cancer, preserve function. For men with localised prostate cancer up to Gleason Grade 2, this balance of oncological control and quality of life is particularly crucial.

Current standard treatments like radical prostatectomy or whole-gland radiotherapy are effective but often come with considerable morbidity. Rates of urinary incontinence, erectile dysfunction, and bowel complications remain significant despite advances in surgical and radiotherapy techniques. These side effects are not merely clinical statistics—they deeply affect patients' emotional wellbeing, relationships, and long-term health. By contrast, focal therapy's minimally invasive nature yields markedly lower rates of life-altering complications. Most men maintain urinary continence, and sexual function outcomes are consistently better than with whole-gland interventions. For health systems emphasising patient-centred care, this shift toward functional preservation is both ethically and economically advantageous.

Rapid deployment is further justified by technological progress in prostate imaging and diagnostics. The widespread adoption of multiparametric MRI, MRI-ultrasound fusion, and targeted biopsy techniques has significantly improved tumour localisation. This imaging revolution allows clinicians to identify and treat only the clinically significant lesion, reducing concerns about undertreatment. For men with Gleason Grade 2 disease—high enough to warrant intervention but often still organ-confined—focal therapy can provide disease control comparable to traditional methods while avoiding overtreatment.

From a system perspective, focal therapies offer operational advantages. They are typically performed as day-case procedures, reduce hospital bed pressures, and allow faster patient recovery. This efficiency is particularly valuable in healthcare environments struggling with surgical backlogs and resource constraints. Furthermore, focal therapy does not “burn bridges”: if the cancer progresses later, patients retain the full range of conventional treatment options.

Patient demand is also rising. Increasing numbers of men seek treatments that balance cancer control with quality of life, and many express frustration that focal therapy is not more uniformly available. Rapid deployment would address this gap, promote equity of access, and align care pathways with contemporary patient values.

Focal therapy represents a mature, evidence-based, patient-centred approach to managing localised prostate cancer up to Gleason Grade 2. With strong functional outcomes, sound oncological results, improved diagnostics, and efficiency benefits for health systems, rapid deployment is not only justified—it is overdue.

Affected Comment:

Yes. This condition has affected me personally. I was diagnosed with prostate cancer following an elevated PSA blood test, which led to MRI scans and subsequent biopsies confirming the diagnosis. At this time, my family and friends have not been directly affected by prostate cancer themselves, but they have been involved in supporting me through my diagnosis and treatment process.

Evidence Comment:

From my perspective, the evidence considered by the UK NSC appears thorough, but there are a few areas where additional emphasis or clarification may be helpful. First, the review could further explore emerging improvements in MRI-first pathways, which have significantly reduced unnecessary biopsies and improved diagnostic accuracy. Second, more consideration of risk-stratified screening—particularly for men with family history or higher genetic risk—may help reflect real-world variation in who is most affected. Finally, the lived experience of men like myself with no symptoms or family history who were diagnosed early through opportunistic PSA testing may offer valuable context when evaluating the potential benefits of structured screening.

Discussion comment:

In my view, the discussion and conclusion in the review do not fully reflect the benefits that an accessible, nationwide prostate cancer screening programme could provide. While the UK NSC has highlighted uncertainties around overdiagnosis and potential harms, these concerns must be weighed against the clear evidence that early detection can dramatically improve outcomes and reduce the need for more aggressive treatment. Modern diagnostic pathways—particularly MRI-first approaches—have already addressed many of the historical issues that previously made screening less reliable.

Given these developments, I believe the current recommendation should be reconsidered. A fully accessible screening programme would offer men equal access to early detection, reduce regional and socioeconomic disparities, and provide structured, evidence-based pathways rather than leaving people to navigate opportunistic testing on their own. For these reasons, I feel that maintaining the status quo does not adequately serve those at risk.

Recommendation comment:

I believe there are strong reasons to support the introduction of a structured prostate cancer screening programme for men. Prostate cancer often develops without symptoms, and many men are diagnosed only once the disease is more advanced. Screening offers the opportunity to detect cancers earlier, when treatment is more effective and far less invasive.

Modern diagnostic pathways—particularly the use of MRI before biopsy—have significantly improved accuracy and reduced unnecessary procedures. This means many of the historical concerns around overdiagnosis and overtreatment are now better managed. Early detection also improves quality of life by reducing the need for radical treatments that carry greater side effects.

A screening programme would also promote fairness. At present, access depends largely on a man's awareness, confidence, or ability to request a PSA test. A structured programme would ensure equal access to early detection, especially for higher-risk groups such as men with a family history or men of Black heritage.

For these reasons, I feel that a national screening programme would offer clear benefits in terms of earlier diagnosis, better outcomes, fewer aggressive treatments, and more equitable access to

Alternatives comment:

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Other comments:

From my own experience as a patient, I would recommend improving the clarity and support offered throughout the whole process. Although the hospital team was fantastic, there was no follow-up or contact from my GP surgery either during or after my treatment, apart from arranging the six-monthly blood tests. This lack of communication left me feeling completely let down at a time when reassurance and guidance would have meant a great deal.

When I first had a raised PSA, the waiting and uncertainty were extremely stressful, and clearer information about what to expect at each stage would have helped enormously. Faster access to MRI scans and specialist appointments would also make a huge difference, as delays only increase anxiety.

Finally, ongoing support after diagnosis—such as proactive check-ins from primary care, access to a specialist nurse, and emotional or peer support—would make the journey far less isolating for men and their families. These improvements, from a patient's perspective, would greatly enhance the overall experience and quality of care.

P142	Affected Comment: No it has not Discussion comment: The repeated comments are over diagnosed and over treated. Surely therein lies the crucial issue – diagnosis needs to be fully explained, the options outlined (different treatments or no treatment/monitoring) and decisions reached with fully informed consent from the patient. If patients are over treated, then the fault lies with the professionals who are over treating. This is what should be remedied, not avoiding diagnosis in the first place. Over diagnosis is not the correct term to use – it is a diagnosis, with different treatment options. Recommendation comment: Yes, I think it should be recommended for risk groups, including black men. No body deserves to have the option of screening and diagnosis withheld if their risk is high. People should have the risks, of screening and treatments, fully out lined and be given the opportunity for fully informed consent. Alternatives comment: What options? This has not been explored or explained.

Affected Comment:

My partner was diagnosed with moderately aggressive adenocarcinoma of the prostate in****. His **** has been living with stage 4 prostate cancer for ****. My partner was **** when he was diagnosed and in full-time work. His stage of prostate cancer means that he has had to take time off work due to appointments, treatment and side-effects of the cancer itself and medication. Although the company he works for is, and has been very good with him, he will soon have to move onto statutory sick pay for any further time-off, which will have a significant impact on our family's finances.

Evidence Comment:

Besides those that have mutations to the BRCA1 and BRCA2 gene, there are other groups of men that are at an increased risk of developing prostate cancer – black men, and those with a family history of prostate cancer. These higher risk groups were not considered in the review, many of whom would benefit from the early detection of prostate cancer.

Discussion comment:

The PSA blood test is not the only diagnostic tool used when testing for prostate cancer. An elevated PSA level would indicate that further tests were needed. The comments surrounding the ineffectiveness of the PSA blood test will have a detrimental effect on the number of men requesting the blood test and potentially lead to more men being diagnosed at the terminal stage of this disease. Prostate cancer responds well to treatment in early stages and the earlier it is found the better the outcome. Earlier detection leads to less invasive treatments with fewer side-effects. I find the findings comments that the impact of a national screening program would only save a few extra lives insulting to those few whose lives will be lost without a screening program. Are those 'few extra lives' not worth saving?

Recommendation comment:

I strongly believe a national screening program for prostate cancer should be introduced. Prostate cancer rarely presents any symptoms in it's early stages when it is at a point that it is very likely to be cured. It is not a cancer that one can detect oneself. My partner attended a doctor appointment in **** for nocturia, thinking he had diabetes, and was offered a PSA blood test, the results of which came back showing elevated levels of PSA. This triggered further investigations which confirmed prostate cancer in ****. He had no other symptoms. He was told if he had waited another 12 months, his outcome would have been very different. Without screening and the detection of prostate cancer, more men with aggressive forms will die.

Alternatives comment:

Education. All men over the age of 45 should be made aware of symptoms of prostate cancer, and their risk factors, and they should be encouraged to seek medical advice if they are concerned about these.

Other comments:

The often cited 'a national screening program would lead to overdiagnosis and overtreatment' is insensitive and insulting to men and the medical profession. In my partner's experience, and the many hundreds of men we have since spoken to after his diagnosis, he was given very clear information about his staging, prognosis, treatment options and side-effects, ranging from mild to

	severe. He was encouraged to consider many factors in deciding his treatment pathway and which would be the best for him and his future health. Presently some 12,200 men's lives are lost every year to prostate cancer. At no point does the NSC indicate how many more lives would be lost to prostate cancer if a national screening program were not to be introduced.
P144	Affected Comment: My husband had annual PSA tests from the age of ***** as his ***** had benign prostate hypertrophy. At the age of ***** there was a spike in PSA that warranted further investigation. My husband had no symptoms at this stage and went for further investigation with a urologist. A digital examination showed enlargement with anomalies. It was suggested immediately there was the possibility that my husband had prostate cancer. Following an MRI and biopsy it was confirmed my husband had cancer. A PET scan followed showing three tumors within the prostate but ***** A radical robotic prostatectomy followed. Yes there were implications to begin with of incontinence and erectile dysfunction which after more than 12 months are now resolved. Regular PSA tests show the lowest level recordable that gives peace of mind my husband is in remission. We did consider alternative treatments but as the cancer was still encapsulated a radical prostatectomy for us would render the best outcome. The PSA test for our men folk should be mandatory screening or added on to regular blood tests. Yes it can show BPH not cancer but to be denied knowing your PSA level reduces the chance of detecting and treating any prostate disease including cancer.

	I believe males deserve the same access to early warning as do females with screening for breast cancer. To suggest it is not valuable or leads to over treatment is counterproductive to the provision of healthcare for all males with a prostate.
P145	Affected Comment: My ***** died from Prostate Cancer and both my ***** and ***** have had prostate cancer. Thanks to early screening my ***** was able to have surgery, didn't require any further treatment and is healthy. I now worry for my husband and in particular my son, as we know this runs in families. Evidence Comment: yes, significant evidence was missed in terms of the importance of early detection Discussion comment: please reconsider this – it will save many lives and money and resources in the future Recommendation comment: yes i believe it should be recommended. it will save lives and money and resources in the future

P146	Affected Comment: Yes, my ***** has prostate cancer and my ***** is affected. Evidence Comment: I believe they dismissed they mistakenly dismissed case for risk-based screening. We know that a family history and characteristics such as race can have a bearing on who develops prostate cancer, and we already have the necessary tests in place, PSA and MRI screening. Why did they not consider piloting risk-based screening for the above groups? Discussion comment: The chair of the committee who looked at this also ran the CQC which has an abysmal record. The committee did not, to my knowledge, include any Black men. They took at face value outdated information about the reliability of PSA tests without considering using MRI screening as well, which is more accurate. Risk-based screening will involve higher costs initially but could end up saving millions if long-term hormone treatment is avoided, as well as chemotherapy and radiotherapy. It's hard not to conclude that cost played a factor in this decision. Recommendation comment: Yes, risk-based screening should be recommended, trialled and evaluated, and then a further decision on universal screening can be made. Alternatives comment: I'm not sure how. there is already quite a high profile for information on prostate cancer. A UK-wide risk-based screening programme would be a very good start.
P147	Affected Comment: My father died of metastatic prostate cancer. If other families can be spared this by targeted screening it should be made available, particularly to high risk groups Other comments: Screening for high risk groups should be implemented with immediate effect it saves lives, and would be cost effective in the long run

P148

Affected Comment:

My husband is high risk due to his ***** having had a radical prostatectomy for stage 3 prostate cancer. He has yearly PSA blood tests as an indicator of levels. I previously worked as a ***** and technology has moved on so less false positives This is probably one of the most common cancers if found and treated early that can be eliminated. The cost of long-term treatment, surgery, end of life care and the burden this has on the man and his family costs way more than a screening programme of a blood test, if indicated MRI scan and then if deemed needed a biopsy. There is no need for every man to be biopsied. The screening programme would cost so much less in terms of finances and patient experience. We have a friend who is ***** by chance was diagnosed this year with stage 2. He has no symptoms and wouldn't have known anything was wrong. Thankfully he is now under the right treatment and costing the NHS very little and still able to enjoy life to the full, rather than having a death sentence hanging over his head.

Recommendation comment:

Screening should be recommended for my views in the first box – screening saves lives and we should be more focussed on prevention rather than cure – it's much more cost-effective in the long term.

I was told at my first mammogram that the first time is not always reliable, and I had a high chance of being called back – same principle should apply for men – not 100% reliable but better than not having any option at all or left to chance

Alternatives comment:

As there can be very little symptoms, a screening programme is the most long-term cost-efficient way to cure prostate cancer.

Other comments:

Don't be so short-sighted that just because the cost savings won't be seen today, a longer-term mind-set with a screening programme will save lives and money at the same time

P149

Affected Comment:

My ***** died of prostate cancer in *****. My father died of stomach cancer *****. My ***** has stage 4 prostate cancer and now bone cancer aged *****. He has received a written apology from his original prostate consultant saying that he should have been put on a six monthly PSA test programme after a digital exam but he failed to pass on that instruction and he was left for two years with no testing. When tested after two years it was too late to do anything. My ***** is fading away!!

Evidence Comment:

Running the NHS so "hot" is a total disaster for so many people. When consultants, under extreme pressure make mistakes people can die !!!!!

I am having 6 monthly PSA tests after medical advice strongly recommended my chasing my local surgery, every 6 months, for the test.

I believe there is an accurate prostate cancer blood test used in America. Why can't it be used here for high risk people. Maybe it is available if you have the funds of course!!

Discussion comment:

Conclusions and recommendations are formed by people working in a broken NHS.

There primary thoughts have to take account of the system they work in and they must not add extra stress to that system.....their primary thoughts should be about the health and well being of the population and how the system could be changed to achieve that.

We will never obtain the correct recommendations using our unchanging NHS systems.

P150	Affected Comment: As someone whose ***** has died of prostate cancer and whose ***** as prostate issues. It seems absolutely bizarre that a simple PSA test cannot be implemented which could save an individual or prolong their life with treatment. It will also negate such high costs for the NHS for latter stage prostate cancers. It is absolutely disgraceful that something as simple as a PSA test cannot be provided to men with direct family members who have prostate cancer. Evidence Comment: The cost of treatment for latter stage cancers Discussion comment: I feel that this is an absolute nonsense and the panel has let the public down sadly. Recommendation comment: It is low cost and preventative measure. the 10 year plan is all about preventative care, Did the panel not get the memo on that when outlining their findings? I am sorry to be factitious, but it is required sadly, as the decision is one of stupidity and lacking in common sense
P151	Affected Comment: My increased PSA over a number of years (less than *****) resulted in my referral. The increasing PSA was due to an enlarged prostate at about *****. After expecting surgery COVID got in the way (thank fully) and another very clued up surgeon recommended PAE, prostate artery embolisation. This has been very successful. As ever NO action on elevated PSA means poor outcomes. Screening over age 40 in white males is essential and in Black ***** males 35 age. Discussion comment: Why try and swim against the tide of both public opinion and that of our European neighbours. As ever in the NHS a lack of leadership and innovation manacle us in the UK to very poor health outcomes Recommendation comment: Screening is cheap and effective compared to the Social cost of premature death to families and the commensurate loss of Income both for the State and the individual. Alternatives comment:

	Regional Prostate Health hubs in all large cities and all counties
P152	Affected Comment: Friends have been affected with many undergoing extensive treatment. Reliance on family history is flawed because life spans have changed rapidly with modern medicine. Evidence Comment: I believe the evidence from screening programs in other countries such as Sweden was not given enough weight. Surely PSA as a first line followed by fast tracked MRI would identify those cancers requiring treatment and those which can be monitored. We are not relying on an unreliable blood test alone. Cervical cancer tests can also throw up false positives which are then identified with colposcopy and the require no further treatment. Cancers being detected by chance at a later stage is poor care. Discussion comment: I believe the recommendation should be reconsidered with a second opinion given by a different committee including other experts. There are always differing opinions amongst ext. Recommendation comment: PSA should become part of the annual blood test for men over 50. It is immoral that the most common male cancer does not have a screening programme available in other western countries and of course privately here. Alternatives comment:

Screening is by far the best tool but it will also need an advertising and advocacy programme to reach and influence minority groups.

Other comments:

This feels like it has been overly influenced by short term costs. As a retired ***** I am acutely aware that preventive measures load cost up front to save in the future. This is a difficult decision for governments to grip when our current political system causes government change every 5-10 years. We need the NHS to be considered by all party groups that are given authority to make long term decisions for the health of the population.

P153	Affected Comment: I received my prostate cancer diagnosis following a consultation in the gp practice with a paramedic technician who suggested a psa test. My cancer was caught early and is treatable. Evidence Comment: Yes I have comments Without the psa test my cancer wouldn't have been identified I had no other symptoms Why haven't you taken views from the black community Discussion comment: Yes it is a wrong decision Recommendation comment: Screening should be recommended Alternatives comment: As one man will die every 45 seconds from prostate cancer in the uk improved screening us needed now and the government and Streeting need to over ride the committees recommendation Other comments: Yes improve the ethic mix on the national committee Where is the representation from the black and Asian men

P154	Affected Comment: According to my GP, I don't have prostate cancer. That is based on a PSA test. This test is known to be inaccurate, and yet the NSC has chosen to not recommend screening for all men who are at risk because of their age. In my opinion, the NSC is being influenced by government, and is putting money before lives. It is a politically-biased decision – no question! Evidence Comment: There is no point in me commenting – it won't change a thing. We have a government which breaks manifesto promises without a second thought. Discussion comment: Yes – the NSC's decision is wrong. Recommendation comment: It should be at least offered. If a male chooses to decline, then that is his decision, rather than the decision of the NSC. Alternatives comment: A national screening programme should be exactly that – NATIONAL. Other comments: Yes – stop prevaricating and change the decision. The NSC should not be the ones who decide whether people live or die.

P155	Affected Comment: It has affected my ***** who was carefully managed and has died at age *****. This was only possible because of the early screening test. He sought screening himself and results were properly evaluated after pre-test counselling. This happened abroad but should be possible here. Evidence Comment: The evidence failed to extrapolate from the breast screening program where initially, there were problems relating to overdiagnosis of benign growths as malignant or pre-malignant. These issues have been dealt with and improved methods of detection are being evaluated. There is no demand for withdrawal of the screening program as it is accepted that benefits outweigh harms with proper application of best practice. Discussion comment: The discussion is flawed. Insufficient weight has been given to the communities with increased rates/deaths from the condition. There is an impression that there is an absence of sensitivity/discrimination in relation to a minority group. The increased access to avenues of education and reliable information is overlooked. The recommendation is incorrect as these factors have not been considered. Recommendation comment: Selected screening should be implemented. It would be cost effective if 1. high risk groups were clearly identified 2. comprehensive information was widely disseminated

P156	Affected Comment: I have lost ***** family members to Prostate cancer. Whilst it is too late for them, I would like to think that my existing family could feel safer with regular screening. Evidence Comment: No comment Discussion comment: No Recommendation comment: Yes, women are offered mammograms and well women clinics. Men should have the same opportunities. Alternatives comment: Ramp up advertising; Offer mobile clinics in city centres & Drs to ask men of a certain age whether they have any symptoms when they visit for any other reason Other comments: no
P157	Affected Comment: Yes, my ***** and my ***** sadly died of the cancer.
P158	Affected Comment: ***** and ***** Evidence Comment: Why do the test for Prostate cancer in Sweden, but not England when they have a lower percentage of black men (at risk group)? Recommendation comment: Should

P159	Affected Comment: I was lucky and was diagnosed with prostate cancer in time for curative treatment. I have friends who have both been treated successfully, and friends who have died from the disease because their diagnosis was too late. Proper screening would have helped to prevent this. Evidence Comment: Not enough emphasis regarding the number of men that have died because their prostate cancer wasn't diagnosed until they had symptoms. Most men do not have symptoms from prostate cancer until it is well advanced, and by then, it's often too late for curative treatment. Recommendation comment: Screening should definitely be recommended. How else will the disease be detected whilst at early, symptomless stage without it? Alternatives comment: Make psa tests available on demand and without argument from GPs, for all men over the age of 45. Too many men get told they don't need a test if they don't have symptoms, which also leads me to believe that GPs need more training regarding prostate cancer, because they should know that disease is nearly always symptomless at early, curable stage.
P160	Affected Comment: Yes. I am a ***** and was diagnosed with prostate cancer *****. I underwent a successful Robotic Prostatectomy in *****. I was planning to retire ***** , so this diagnosis prompted me to retire fully. My family and friends have been fully supportive of my decision. I was having my PSA checked annually, but missed a year and it had gone up significantly to *****. I was subsequently diagnosed with a significant multifocal tumour which would most likely have progressed beyond cure within a year or two. Biopsies are not particularly pleasant, but the robotic prostatectomy was far less disruptive than I had imagined. I am indebted to the NHS for their wonderful care. What is some erectile dysfunction and occasional slight leakage compared with being cancer free and drug free. Evidence Comment: The problem is that there are few patients now who haven't had a PSA so screening studies are biased. Discussion comment: I remember a wise professor telling an audience that just because there was no evidence proving an intervention was effective doesn't mean that it isn't effective. Recommendation comment:

	We have to start somewhere, it will evolve with time, but over 50000 new cases and over 12000 deaths per year means that something has to be done. It may not be perfect to begin with, but doing nothing should not be an option. Alternatives comment: You need more urologists, radiologists, pathologists, oncologists, specialist nurses, with more MRI scanners and Robots. That way you can spend more time with patients and correctly identify those that need biopsies, treatment or monitoring, and have it explained to them in a way that is timely and that they can understand. Other comments: I think an annual PSA is more appropriate as it is much easier to remember and organise. A PSA at the time of an annual GP check, taken close to the patients birthday as some surgeries recommend. It will detect the more rapidly growing tumours. 梔劄畝癥帔磁埤硯彪幣孳祺愠黼吮兹

P161	Affected Comment: Yes Evidence Comment: No Discussion comment: I think the conclusion does not match the evidence. Non invasive MRI for high risk screened patients offers very little risk. The benefits of screening do outweigh the risk in my view Recommendation comment: Should be recommended as up to date practise offers little risk and much benefit. Alternatives comment: No comment Other comments: Read the ten year an for the nhs re left shift.
P162	Affected Comment: This is an absolute must do, if caught it can save lives, and I have real life experience with a friend. Recommendation comment: Absolutely should Alternatives comment: There are surely alternatives to screening, such as testing key factors..

P163	Affected Comment: Prostate cancer has affected some of my family members. Evidence Comment: No Discussion comment: I agree with screening of men with BRACA 1 and 2 gene, but believe the cohort included should be extended to at least 75yrs (and maybe even 80yrs). The arbitrary cut off at 61years seems unfair, too limiting and bias to exclude older men. Recommendation comment: Recommended with expansion of upper limit age to at least 75yrs Alternatives comment: Think screening is important – also could try and develop a test similar to that we use for bowel cancer – that could be an initial home test in postbox drop or something. Other comments: Yes expand the age group 61 years for BRACA GENE cohort is too low.

P164

Affected Comment:

I have several friends who have been diagnosed with Prostrate Cancer. all have been affected in several health ways. by their own struggles with the after effects i get myself screened each year. It is an important action that I take. Importantly I am the major wage earner in the family to be affected by this would seriously impact on my life as well as the dependants I support.

Discussion comment:

To consider scrapping this vital testing which is important to all males but also to a majority of the main income source of family life. Males who have to wear pads and pants could affect their ability to continue manual labour and all other physical trades, and a possible resultant in unable to work and the possibility to welfare, another cost to the over stretched Island

Recommendation comment:

Yes as in the above statements. There is a high rate of prostrate cancer, Would you then decide to stop breast cancer screening? And I could say that the actions you would be considering is purely a sexist action.

Alternatives comment:

Then please instead of scrapping this service provide these NEW alternatives. But there should be NO COST to us.

Other comments:

I think a television informative advertisement should be produced showing no only the procedure of a simple test but also the affects of prostrate cancer on males, with no bars attached. For example No more Erections, possible incontinence, and the mental awareness that this condition could be on the affected male

Affected Comment:

I have one friend who got treatment for an aggressive prostate cancer only after appearing on ***** bemoaning the delay threatened by the local NHS trust. He wouldn't have known he'd got it without tests.

Another friend was less lucky; his spread around his body and left him increasingly sick and disabled until he died. I believe screening could have saved him.

My own experience follows a prostate infection ***** years ago. Since then, I have tracked PSA levels, conscious that a sharp rise is more indicative of cancer than the absolute level. So far, so good, and some tissue removed in a recent TURP was subjected to a negative biopsy.

Evidence Comment:

The evidence missed was the success of targetted screening in Sweden and other countries.

This evidence implies that targetted screening would be even more efficacious in the UK, where we have a larger black population, who are subject to double the rate of prostate cancer as white men. If screening saves lives and medical costs in Sweden, it would save even more here.

There is no need to go straight from initial suspicion to intrusive biopsies, and several other tests exist, including scans. There are other blood tests under review, that could reduce false positives and missed instances.

Discussion comment:

The justification for denying British men targetted screening is based on flawed and perverse logic --The very groups that make England different from Sweden and Germany are the groups at higher risk... black men who have roughly double the incidence and double the mortality.

If Sweden can justify targeted screening with a lower-risk population, how can England justify refusing it in a higher-risk one?

Recommendation comment:

I feel strongly that screening should be offered to all at-risk groups, including those with a family history of prostate cancer, and members of minority groups with higher incidence of the disease. Screening should progress involve scanning before biopsy, to avoid harms from overdiagnosis.

Not only would this reduce suffering, but it would potentially save the NHS the costs of treating stage 3 prostate cancer.

The current recommendation is discriminatory, in that it condemns more men than women to a painful and undignified end, and will have a bigger impact on black than white men.

Alternatives comment:

Without screening, it might well be too late to help.

The NHS will need to invest more in hospice care.

Other comments:

	Please reconsider. Ask yourselves whether the reviewing body should be more representative of the affected population – rather than all-white and predominantly female.

P166	Affected Comment: Yes directly affected through the death of my *****. Saw first hand the devastating impact of losing him and also how losing his own family members to the illness impacted him before his passing. The impact was also huge for my ***** including detrimentally to their mental health. I am also acutely aware of the risk posed to myself being a son of afro caribbean parents. Paying for my own test annually. Evidence Comment: No other than to day there are numerous bodies of evidence that counter the argument not to screen. I would question whether or not sure consideration has been given to the same. Discussion comment: Yes. I know of numerous instances where late intervention has led to the untimely death of many individuals of BAME heritage. Early diagnosis is highly likely to have reduced the loss with earlier diagnosis taking place. Recommendation comment: Yes should be recommended for the reasons mentioned above. This should be linked to education and raising awareness at a younger age. Alternatives comment: See above. To my mind screening and testing at an early stage can save lives. Despite the concerns around false positives and negatives. Other comments: Nothing that has not already been mentioned.

P167	Affected Comment: I had prostate cancer in *****, there was no family history and no symptoms. I was only tested as my friend had been through this so I decided to get a test. It turned out to be cancer and at Stage 3 with a PSA that went from ***** in the course of a couple months. Had I not been tested at the start of *****, I wonder where I would have been by now. It would have probably made itself known when it was too late. Evidence Comment: There was no evidence tests identified that I had cancer. Discussion comment: Please make National Screening for Prostate Cancer an established test for men over the age of 50 (at least) to save lives. Recommendation comment: If I had been routinely screened, it would have picked up I had cancer earlier and at an earlier stage. Far easier to treat and less impact on my health. Alternatives comment: Promotion of screening. I know two men who had elevated PSAs with no cancer and 5 for whom intervention saved their lives. Other comments: Please just make screening part of a checkup

Affected Comment:

I am ***** and was diagnosed with prostate cancer *****. I had PSA tests along with other blood tests (well man screening) annually from aged *****. My PSA gradually crept up and following a DRE (digital rectal examination) at my GP, was referred to a consultant. I was given the option of a biopsy, which I took and this gave a Gleason score of ***** confirming the cancer. I was offered alternative treatments and settled on LDR brachytherapy, which was successful with very little side effects.

My best mate was less fortunate. He was diagnosed with advanced prostate cancer when he was *****; which had already metastasised. His first PSA was well over 30. It had already spread to his bones and he died when he was *****. Had he been screened and caught early he would still be alive today.

Evidence Comment:

No mention was made of the DRE test in conjunction with PSA test as a form of screening – detecting an enlarged or lumpy prostate for cancer or other prostate problems.

Discussion comment:

The discussion, conclusions and recommendations are flawed and seem to have been already decided against a screening programme.

Recommendation comment:

Yes screening should be universal for all men. Annual PSA tests would give each man their benchmark reading, which if increasing over time with or without symptoms, would lead to a DRE. Biopsy should then be offered as the next step, to confirm or not. Options of treatment or watchful monitoring should then be offered.

Alternatives comment:

What a stupid question. Screening is the only way forward.

Other comments:

More publicity on prostate awareness

P169	Affected Comment: Yes my brother in law Evidence Comment: I'm really concerned that the make up of the panel couldn't review the information without bias it's not representative of the population and I'm unclear if lived experience was considered and if the NHS is not about the people then I don't know why it exists Discussion comment: Men deserve equity and equal life chances the NHS needs to learn and innovate this feels like an out dated process to decide something so important Recommendation comment: Yes because it works in mother countries Alternatives comment: Proper national men's screening process re vamp health checks long overdue Other comments: Act with pace someone has died whilst during my response and focus the CQC on his reform mission so it can be credible during this process and a large consultation do be place re the NHS you have the detail actively seek the answer from that database

P170	Affected Comment: Yes my father was recently diagnosed with stage ***** cancer of the prostate which has metastasised. This immediately puts me at higher risk of developing the disease. He presented late following symptoms (urinary incontinence). I'm of the view that screening would have given him a much better chance of long term survival. Evidence Comment: Some of the comments in your summary directly contradict what I've heard directly from clinicians involved with my fathers care so I'm not sure that I believe the conclusions reflect clinical consensus – just the state of the evidence, which is a poor basis for decision making in my view, it should be more nuanced. Discussion comment: Yes, as above. In my opinion relying solely on research evidence but ignoring evidence from clinicians and survivors and their families is a poor basis for making complex decisions. It is reductionist. Recommendation comment: SHOULD. See above. Alternatives comment: Education obviously – the public and clinical staff. At risk groups should be targeted. Other comments: Introduce routine screening for high risk groups post 55 years.

P171	Affected Comment: Having lost my father and brother at ***** and ***** respectively, I didn't have any family history to pull on. However, I was offered the PSA test in a works welfare medical aged *****, which I took advantage of. The test identified that I had a raised levels (*****) and I then went through additional tests and a biopsy which identified that I had low grade prostate cancer. This was monitored for ***** under an active surveillance programme, during which I contracted sepsis from a rectal biopsy. A further biopsy was undertaken *****, which was the safer transperennial biopsies. Due to elevated PSA levels (*****), I opted for robotic surgery at *****. The operation went well and recovery and follow up test results have been good over ***** Evidence Comment: I am confident that the evidence was reviewed, however in my case now *****, if I hadn't had the wellness medical at ***** my diagnosis would have been missed. Discussion comment: based my personal experience and others I have spoken to, the conclusion to not implement a screening programme is flawed and all men over 50 or 45 ***** should be screened. Recommendation comment: See previous commentary Alternatives comment: There will be many people like myself who do not have a family history to pull on, as such I feel men should have a screening programme from 45 Other comments: No further recommendations

P172

Affected Comment:

I visited a duty GP in ***** as my GP was unavailable. I gave no thought to a prostate problem. I talked about an unexplained weight loss and a niggly lower back pain. A blood test and X-ray were arranged. The GP then asked me the question that saved my life. "How are you urinating" she asked, and I replied that I have had to wee during the night more often recently. The second question that also contributed to successful cancer treatment was "May I conduct a physical test, please." At this point I was placed on the urgent pathway, had a MRI in ***** , a biopsy in ***** , confirmation of prostate cancer a little later, and a prostatectomy in ***** . I was declared cancer free in ***** , but was informed that in another week or two the cancer would have spread. The point I wish to make is that my PSA was marked as normal on my NHS app by my GP, and he also wrote that no action was required! The physical test, administered by the duty GP had saved my life. In all that I have read about the upcoming review, little has been written about the physical test that saved my life.

Evidence Comment:

Please, please include the physical test in the plans, As my PSA test result was normal. Without the physical test, I would not have been treated for prostate cancer. By ***** the cancer would have spread, and I would have been a stage three cancer victim, with no symptoms. The worst case scenario is that I would be a stage four victim with no hope for the future. The physical test must be included in the review.

Discussion comment:

Please include the physical test

Recommendation comment:

The PSA test is not reliable enough. We must use tests made available by further research. We must find a place for the physical test, that was administered by the duty doctor, as it was that test that saved my life!

Alternatives comment:

If a GP feels that there is any chance of prostate cancer, then the physical examination must be administered. The time that an MRI takes to be administered is too long. The physical test saved my life!

Other comments:

No

P173

Affected Comment:

Yes. As a member of a high risk group; a Black woman of African Caribbean origin. My late ***** died of this. 1 in 4 Black men are affected. A family friend was incorrectly diagnosed for ***** years and died of it. The evidence in our community is irrefutable. No

Evidence Comment:

I do not know if the NSC, considered the report of Prostate Cancer UK. The composition of the NSC itself is problematic as there does not appear to be one Medical professional with a specialism in men's health. As men constitute about 50% of the population, I question the ability of the members to have indepth knowledge of specific male health problems and in this case prostate cancer in Black men.

The committee itself, as I understand it, lacks the clinical knowledge to pronounce on this issue related to male health. I am astounded by this apparent omission.

Discussion comment:

The recommendation not to roll out prostate cancer screening appears to be based on the cost of the roll out. The argument is flawed as a targeted screening of those in high risk groups (proposed by PCR) would in fact identify cases early and save money later when advanced cases have to be treated with aggressive medical strategies.

Recommendation comment:

Screening should be recommended to save the lives of all men who die from the condition. Early detection would identify cancers early and with this a range of life extending treatment options. Black men are high risk here. I do not understand why research has not helped us to understand why this is.

Screening would provide early treatment options. In addition to this Screening, Medical professionals need to be trained to identify early symptoms men in high risk groups. This does not appear to be the case currently.

Alternatives comment:

Only screening can identify potential cancers early enough for life saving strategies to work.

A public health education programme alongside the screening programme could be helpful with well known celebrities encouraging men to be screened plus ordinary people who lost loved ones because they were misdiagnosed by GPs or presented to the NHS late.

If this committee, with its limited knowledge and lack of expertise in male health pronounce that a screening programme for men is not necessary, it will be condemning men in high risk groups who already have a distrust of the NHS, to death, in order to 'save' money. This will send the clear message to those in the high risk group that their lives do not matter; by policy, that Black male health does not matter.

Other comments:

The constitution of the committee needs to be changed to cover the health needs of women, children, teens AND men.

Male health matters. Appoint a suitable man with training and experience in Andrology. This is a woeful omission from such a committee which pronounces on the health of the population.

Affected Comment:

I am a *****.

In ***** aged ***** my PSA was very low and no concern.

In ***** (after arguing with the GP for a PSA test please) still aged***** since previous result, it was 14.3, meaning an apology from the GP plus: MRI, then biopsies, then hormone treatment for 6 months and radiotherapy for 30 days, I am now in remission.

Psa should be routine screening every 6 months, the horrors of my colleagues and friends dieing due to prostate cancer and because not checked in time is inexcusable!

PSA test, with instructions: not to have sexual activity/ride a bike/weight training to ensure the health of the nation and to address the inequality of routine screening for women for similar.

Evidence Comment:

Why do you have the CQC failed leader in charge, it should have been a consultant urologist!

I am a *****.

In ***** aged ***** my PSA was very low and no concern.

In ***** (after arguing with the GP for a PSA test please) still aged***** since previous result, it was 14.3, meaning an apology from the GP plus: MRI, then biopsies, then hormone treatment for 6 months and radiotherapy for 30 days, I am now in remission.

Psa should be routine screening every 6 months, the horrors of my colleagues and friends dieing due to prostate cancer and because not checked in time is inexcusable!

PSA test, with instructions: not to have sexual activity/ride a bike/weight training to ensure the health of the nation and to address the inequality of routine screening for women for similar.

Discussion comment:

Yes. It should have been lead by a consultant urologist.

I am a *****.

In ***** aged ***** my PSA was very low and no concern.

In ***** (after arguing with the GP for a PSA test please) still aged***** since previous result, it was 14.3, meaning an apology from the GP plus: MRI, then biopsies, then hormone treatment for 6 months and radiotherapy for 30 days, I am now in remission.

Psa should be routine screening every 6 months, the horrors of my colleagues and friends dieing due to prostate cancer and because not checked in time is inexcusable!

PSA test, with instructions: not to have sexual activity/ride a bike/weight training to ensure the health of the nation and to address the inequality of routine screening for women for similar.

Recommendation comment:

Of course it should be recommended. Unless you are an uncaring and making backwards steps for public health.

I am a*****

In ***** aged ***** my PSA was very low and no concern.

In ***** (after arguing with the GP for a PSA test please) still aged***** since previous result, it was 14.3, meaning an apology from the GP plus: MRI, then biopsies, then hormone treatment for 6 months and radiotherapy for 30 days, I am now in remission.

Psa should be routine screening every 6 months, the horrors of my colleagues and friends dieing due to prostate cancer and because not checked in time is inexcusable!

PSA test, with instructions: not to have sexual activity/ride a bike/weight training to ensure the health of the nation and to address the inequality of routine screening for women for similar.

Alternatives comment:

No there is not! There's no substitute for public health screening.

I am a *****

In ***** aged ***** my PSA was very low and no concern.

In ***** (after arguing with the GP for a PSA test please) still aged***** since previous result, it was 14.3, meaning an apology from the GP plus: MRI, then biopsies, then hormone treatment for 6 months and radiotherapy for 30 days, I am now in remission.

Psa should be routine screening every 6 months, the horrors of my colleagues and friends dieing due to prostate cancer and because not checked in time is inexcusable!

PSA test, with instructions: not to have sexual activity/ride a bike/weight training to ensure the health of the nation and to address the inequality of routine screening for women for similar.

Other comments:

Put the correct professional in charge of commissioning a review/report.

It would take 5 minutes for a consultant urologist to determine that it is in the public best interests for a public funded psa health screening program.

I am a *****

In ***** aged ***** my PSA was very low and no concern.

In ***** (after arguing with the GP for a PSA test please) still aged***** since previous result, it was 14.3, meaning an apology from the GP plus: MRI, then biopsies, then hormone treatment for 6 months and radiotherapy for 30 days, I am now in remission.

Psa should be routine screening every 6 months, the horrors of my colleagues and friends dieing due to prostate cancer and because not checked in time is inexcusable!

PSA test, with instructions: not to have sexual activity/ride a bike/weight training to ensure the health of the nation and to address the inequality of routine screening for women for similar.

P175	Affected Comment: My husband was diagnosed *****. He had no symptoms and no family history. He requested a well man MOT and also requested a PSA test as my father passed away to prostate cancer. The GP refused to do the test. My husband lied to the GP saying he could feel something whilst *****. His PSA came back at ***** and 2 weeks later was *****. After all tests he was diagnosed st Stage 3, prostate could not be removed because they could not guarantee full removal of the cancer cells. If screening had been widely available this may have been caught earlier, Australia now screen from age 40 so why isn't the UK doing this. My husband's cancer has had a massive and serious impact on our lives together. We now have a big black cloud hanging over us when we should be preparing for a full filing retirement, I'm just glad he lied to the GP as otherwise my husband would have been handed a death sentence. Evidence Comment: I'm concerned that work and environmental factors have not been taken into consideration. My husband served in the Army for *****. During his service little to no health and safety was paid to diesel emissions from armoured vehicles, there was no extraction. I believe this could be a massive issue with more PC cases from the Armed Forces. Discussion comment: Bloody wrong, test men regardless of age, genetics or colour. Recommendation comment: As above, screening could have potentially diagnosed my husband earlier which might have required less treatment therefore safeguarding NHS funds and actually prolonging a tax payers life. Alternatives comment: More advertisement of the dreaded disease, we do this for women do why not do it for men. Also GPs should not refuse to test, adding to that they should as per NICE provide counselling regarding the PSA test which my husband did not receive Other comments: TEST MEN

P176	Affected Comment: I was diagnosed Gleason (4+3) ***** after routine PSA tests. Now in remission after ADT and radiotherapy. I understand PSA can give spurious results from test to test, but my diagnosis was made after ***** successive tests showed a consistant rise over ***** years followed by a sharp increase. Point tests can be misleading, but a trend not. Recommendation comment: Recommended – even if not free to end user.
P177	Affected Comment: I had to watch my dad die from prostate cancer, it was agonising for him to be suffering and for us, his family, to see. Evidence Comment: If the decision makers had to witness this, in a heart beat they would authorise screening for prostate cancer. PSA tests may not be the most accurate, but they can lead to further screening which may be able to rule a confirmed diagnosis either in or out. As a women, I am fortunate enough to have cervical screening, as an older woman I am fortunate enough to have bowel and breast screening. Surely prostate cancer screening will also save £m when this awful disease is caught early. It's true it may not diagnose all cancers, but screening of any type isn't 100% guarantee to catch all cancers. You only have to visit an oncology ward to see the devastating effects of this disease, please make this happen, even if the decision is to save money, the fact it may well save lives as well has got to be a good enough reason. Discussion comment: If the decision makers had to witness this, in a heart beat they would authorise screening for prostate cancer. PSA tests may not be the most accurate, but they can lead to further screening which may be able to rule a confirmed diagnosis either in or out. As a women, I am fortunate enough to have cervical screening, as an older woman I am fortunate enough to have bowel and breast screening. Surely prostate cancer screening will also save £m when this awful disease is caught early. It's true it may not diagnose all cancers, but screening of any type isn't 100% guarantee to catch all cancers.

	You only have to visit an oncology ward to see the devastating effects of this disease, please make this happen, even if the decision is to save money, the fact it may well save lives as well has got to be a good enough reason. Recommendation comment: If the decision makers had to witness this, in a heart beat they would authorise screening for prostate cancer. PSA tests may not be the most accurate, but they can lead to further screening which may be able to rule a confirmed diagnosis either in or out. As a women, I am fortunate enough to have cervical screening, as an older woman I am fortunate enough to have bowel and breast screening. Surely prostate cancer screening will also save £m when this awful disease is caught early. It's true it may not diagnose all cancers, but screening of any type isn't 100% guarantee to catch all cancers. You only have to visit an oncology ward to see the devastating effects of this disease, please make this happen, even if the decision is to save money, the fact it may well save lives as well has got to be a good enough reason. Alternatives comment: You need a reliable screening programme or invest in finding a vaccine to eradicate the disease Other comments: Wake up Wes, stop ignoring what really matters to people. For once do the right thing

Affected Comment:

No.

Evidence Comment:

I am a cancer patient, not of prostate cancer, and know others who support patients. A major problem lies in the initial assessment, in initial identification of the cancer tumour, and, especially if the prostate cancer were aggressive, an unacceptably long wait between the sending of the tumour and the return of the analysis from the haematologists. In my case a wait of ***** months was deemed lengthy but not totally unusual. This must create challenges for the treating specialists in planning and receiving prompt feedback. The nature of the disease could have already changed by then so the analysis would be historical not contemporary.

I would respectfully ask the people reading this to visit the site of CellBxhealth.plc. This British firm offers an analysis by its treatment product – the Parsortix PC1 system, which is a CE marked and FDA cleared, for the capture and harvest of intact CTCs from metastatic breast cancer blood for subsequent user validate analysis. By means of clinical trials it could form an effective means, if successful, of saving many lives by identifying potentially aggressive cancers at an early age, and by giving rapid feedback as to the effectiveness of recognised interventions. In a recent edition of a European cancer journal, some major oncologists predicted that in five years this method could become the standard way in Europe of identifying cancers. This information is on the above website.

Discussion comment:

I feel the decision to rule out a particular intervention should not rule out consideration of other possible interventions. The decision appears premature and myopic given the issues that are at stake. There might need to be some urgent priority given towards seeking to establish an evidence base towards any alternative decided. Even if this method of screening were not agreed, it could be used in compliance with NICE guidelines to assist in monitoring the treatment process. There is a great deal of evidence on the website of its effectiveness as a treatment aid by Professors of Oncology.

Recommendation comment:

I think it should be recommended for the reason given above. If this were not considered – perhaps with initial trials – I feel the enquiry could lay itself open to future criticism. Many people would die needlessly and many families could suffer.

Alternatives comment:

Health professionals and concerned civilians can do a lot, but I don't think these efforts could ever replace a safe, reliable, and prompt screening process.

Other comments:

I feel the statistics used to measure performance must simply look at areas of treatment identified by practitioners, so that they move beyond the important headline figures of waiting lists and serve also to increase efficiency and excellence in British services. For the issues identified above there is clearly a postcode divergence. Learning consistently from other services overseas would also contribute towards meaningful statistical evaluation.

P179	Affected Comment: Friends have been affected, not family. Recommendation comment: Screening should be recommended. A number of countries already carry out targeted screening, reducing the emotional burden on families and improving health outcomes at a reduced cost to the system. Sweden has a much lower at risk population than the UK, but carries out targeted screening in line with NICE guidance for family history (first or first and second degree relatives). Even the US carries out risk based screening. Like all prevention and screening decisions, the system must be prepared to spend in advance on screening, while continuing to spend on treatment for those not picked up in screening. Over the longer term this will reduce costs significantly while improving health outcomes. However, since this is likely to be a political decision extending beyond the life of this parliament I fully expect the morally correct decision to be turned down in favour of a very short term cash saving view. This rate of spend is almost guaranteed to increase, putting an ever higher burden on an already overstretched system, both for patient care and funding.
P180	Affected Comment: I have several friends and an uncle who have had prostate cancer diagnosed and treated. Discussion comment: They seem to have dismissed findings from other countries in northern Europe that screening works. Bizarrely, on the basis that their populations have different demographics to ours. And yet these differences make their populations generally less susceptible. Our population includes a higher percentage of black men who are especially at risk (double the incidence and double the mortality). As Roy Lilley asks in his nhsmanagers newsletter : "If Sweden can justify targeted screening with a lower-risk population, how can England justify refusing it in a higher-risk one?" He also correctly points out that the logic that applied previously to the unreliability of the PSA test are no longer relevant. MRI scanning and refined risk profiling now prevent over treatment. Recommendation comment: Yes – the evidence suggests that it would (a) save lives and (b) cost the NHS less when accounting for the reduction in late stage treatment required. Other comments: The committee should have included more men and at least one (arguably more given the risk profile) black man.

P181	Affected Comment: Yes, my cousin died of the disease. It don't agree that men shouldn't be screened. What's the alternative. A psa test which doesn't give true results. I don't understand, given that a huge majority of men will die from the disease unless detected before it becomes too advanced to stop! Evidence Comment: All said above. Discussion comment: See above please. Recommendation comment: Please see above. Alternatives comment: Please see above Other comments: Please see above.
P182	Affected Comment: My husband currently has stage 4 prostate cancer. We don't know at this stage how long he has and don't particularly want to know. We are living each day as it comes. BUT living with the worry (from my point of view) every day IS a strain and a worry, it could have all been avoided with a simple test MUCH early and initiated by GP screening. Recommendation comment: The only warning that my husband had was the he was up more during the night to pee. Had I not press ganged him into seeing the GP we wouldn't know. There are many stages to go through before having unnecessary surgery so a simple blood test would give Drs an indication that something isn't quite right. Then there would be MRI's and

	scans before any major surgery so the NSC's argument doesn't make any sense to myself and millions of others. Its a simple, inexpensive test, its a warning AND more importantly WILL save many lives. As women we have breast and cervical screening, what do men have? Nothing!
P183	Affected Comment: I have had patients and distant relatives suffering from prostate cancer, but am not personally affected I am of a medical background but neither an urologist, not a cancer specialist As a medical leader i oversee services who treat the condition Evidence Comment: There is evidence form close related countries that screening works for this condition, even in countries where the population has a more homogenous population and less risk groups like black men then the UK has It is difficult to understand why those lessons are not taken on board Services are struggling with delivery of current demand and screening could within time reduce the demand be cost effective rather then require more investment in curative services. Quality of life in patients who are diagnosed later and treated later is more severely impacted Discussion comment: I am not sure if the review misses important points, but form a NHS constitutional right that could almost be seen as a gender discrimination case, as women's most common cancer is allowed a screening programme, whereas mens' is not. That specifically men form a less privileged background and specific race suffer form it makes it even more problematic Please review this decision Recommendation comment: It should be recommended, at least for high risk groups if not all men over a certain age Alternatives comment:

	there is no alternative to a screening programme for early recognition

	Other comments:

	NA

P184	Affected Comment: Yes – my ***** husband had prostate cancer diagnosed in *****. He had more fréquent urination and went to his GP for a test. After diagnosis – it was not very early stage – he opted for an operation. This was delayed for 6 months due to the pandemic. It was a very frightening period for our family. He has been clear of cancer for 5 years. Evidence Comment: I think the Swedish research sounds very compelling. I think it must be even more compelling for a country with a much larger population of black men where the risk of prostate cancer is much higher. Discussion comment: I think it is wrong to conclude that screening is not needed. Recommendation comment: I think screening should be recommended. I have heard enough arguments from those who want national screening to be persuaded. Alternatives comment: I think both and, not either or. Other comments: The government should over turn this recommandation and fully fund a screening programme. A research project should accompany it, based on the Swedish modèl, and review after 5 and 10 years.

P185	Affected Comment: I have had locally advanced prostrate cancer and my brother has also had it. Evidence Comment: I firmly believe that screening should also include black men and anyone that is worried that they may have this. PSA with a raised level above 4 should be acted upon. I was put off having a PSA test by my GP because of possible false readings for a number of months. After finally having a PSA test I got a phone call the next day saying it was highly likely that I had prostate cancer (PSA *****) a biopsy followed shortly after confirming that I had Prostrate Cancer. A MRI scan, CT and PET scans confirmed that the cancer had escaped from the prostrate in lymph nodes near by. This resulted in ***** sessions of radiotherapy followed by ***** of hormone injections. An earlier diagnosis might well have reduced the treatment required. Discussion comment: Whilst PSA tests may give a false reading on occasion a follow up biopsy will give a definitive result. This should be made available to all especially if the initial PSA test level is significantly raised. Recommendation comment: No Alternatives comment: There are changes that may be in the pipeline and a small (at home) blood test could make a big difference especially those, like myself that had no symptoms apart from going to the toilet a couple of times a night. Fairy usual for someone of an age. GPs should not put men off having the a PSA test as delays can significantly affect possible treatment choices. In my case locally advanced cancer.

P186	Affected Comment: I was diagnosed with prostate cancer in *****. My excellent GP ordered a PSA test, followed by ultrasound, MRI scan and a biopsy. I was diagnosed with a slow growing cancer. Gleeson 6. After ***** monitoring, the cancer grew and was potentially going to breach the capsule, I chose a radical prostatectomy. I've been Cancer free for ***** years. Screening is so important. Particularly for those men who are black and for people like my ***** son. This is not about economics, this is not about false positives. This should be all about targetted prevention. Wake up and give me a fighting chance. Evidence Comment: Plenty of evidence from Prostate cancer uk Discussion comment: As above Recommendation comment: Yes it should be for black men and for people like my ***** son. If 1 in 4 black men are likely to get prostate cancer, why do we do readily deny them a test? Alternatives comment: If there are many alternatives, what are they? Other comments: Test the groups as recommended by Prostate Cancer UK

Affected Comment:

***** died after a late diagnosis of Gleason Grade group 5 Prostate Cancer. As a result, I insisted on regular annual PSA testing and, when my PSA crept up over 5, I went through the very efficient testing program of rectal exam, MRI scan and biopsy which discovered Grade group 3 cancer (Gleason 4+3). I had RT.

Evidence Comment:

I have read about some of the studies which were used and I think that the results are surprising and I have concerns, both conceptually and statistically.

The major objection to widescale screening is overdiagnosis and overtreatment. Accurate diagnosis only comes after several, progressive diagnostic procedures ending with a biopsy. The results from those needing biopsy seem quite clear and the tumours can be graded using Gleason scores and grades. It was put to me that only patients with Gleason 4+3 and higher are recommended for active treatment intervention.

There has been no 'overdiagnosis' (simply diagnosis) but why are patients with Gleason 3+4 or lower offered surgery or RT when it is unnecessary ? Is there proper communication with patients at this critical stage ?

My main problem is that the review mistakenly confuses the combined effect of insufficient communication with patients and inconsistent adherence to treatment guidelines offered by Gleason, as the effects of screening. They are very different in my view.

Screening gives the results on which treatment can be based and consistently applied – we would not then be overtreating people with Gleason Grade 1 and 2 Cancers.

It is not the screening which is at fault.

Discussion comment:

The conclusions are very poor indeed in the sense that there is virtually no discussion of the issues mentioned above.

After my diagnosis it was virtually impossible to speak to an NHS person to discuss options and treatments. When I did meet with professionals the communication skills displayed were very poor and I never managed to get an early opportunity to speak to an Oncologist. Highly paid surgeons, it seems to me, are better employed in their operating theatres and the money saved, invested in trained communicators. This should give much better value for money. Why would the system allow treatment to patients who clearly don't need it – that seems unnecessary as well as costly.

The word 'overdiagnosis' is a poor choice and unnecessarily emotive. It is simply a diagnosis of a relatively mild condition and follow up should not involve surgery or radio therapy with the problems set out in the report.

Recommendation comment:

Yes.

	It will save lives and will not, of itself, lead to “overdiagnosis” or overtreatment if proper clinical rules are set out and exercised consistently. If I had not sought screening after my ***** death I would probably have a much shorter life expectancy now. Screening should be offered to all the high risk groups and be available on request for others. The availability of advanced treatments like MRI guided RT should be made available on the NHS and bowel protection for Standard RT should also be standard practice. Both can significantly reduce side effects for those needing active treatment. Alternatives comment: Availability of trained communicators in NHS hospitals Other comments: Have a route which does not retain patients in Urology departments without a referral to Oncology within, say, 2 weeks of diagnosis.
P188	Affected Comment: I had prostate cancer and without the test I would have never known Recommendation comment: It should be recommended so that we can save men's lives

Affected Comment:

My Father had elevated levels in testing, with borderline levels, resulting in uncertainty as to whether to proceed with further diagnosis.

Multiple friends have been diagnosed and have recovered, whilst two sadly passed away.

Evidence Comment:

<https://www.topdoctors.co.uk/medical-articles/the-use-of-psa-and-mri-for-prostate-cancer-diagnosis/>

Multiple sources including the one above focus on effectiveness of MRI.

Recent guidelines now recommend a more integrated approach: using PSA as an initial screening tool and, if levels are elevated, following up with a multiparametric MRI (mpMRI) before performing a biopsy. This strategy balances the need for early detection with the importance of avoiding overdiagnosis and overtreatment.

Learning from other countries' work on this, such as those in Scandinavia, would be helpful.

Also see <https://pmc.ncbi.nlm.nih.gov/articles/PMC9326692/>

Discussion comment:

Family history, population screening and risk stratification can result in the best diagnoses and outcomes whilst minimising over treatment and over diagnosis.

Recommendation comment:

Yes – early detection is vital and the case made for overdiagnosis and treatment appears not be based on the latest evidence.

Upfront costs for the screening programme will result in significant outcome improvements and longer term savings by saving lives and reducing the costs that late stage treatment results in.

Alternatives comment:

Public health campaigns for awareness.

Targeted screening if full population is impossible. Focus on high risk groups and worst deprivation score areas and groups to help those who are least likely to request screening themselves.

Other comments:

Implement the population screening to save lives.

Alternatively, pilot in two ICS areas with a sufficient timeframe to provide evidence for or against full population screening and let the results speak.

P190	Affected Comment: I have several friends who have suffered the condition. Some died others are in treatment or have received treatment. My frequent toilet trips worry me. Evidence Comment: Evidence of successful screening programmes in other European countries was not “missed” it was dismissed ! Discussion comment: The review panel could have been constituted better. Eight women and three men with no black men, who are major sufferers. The recommendation seems based on old diagnostic techniques. The dismissal of succesful European testing practices was just beyond credulity. Recommendation comment: Of course it should be recommended. Compared with the testing of womens common cancer areas, breast, cervix and ovaries, well there is no comparison is there ? If women were treated like this there would, rightfully, be uproar. It may save many of the 32 men who on average die from it every day. I have no figures for how many suffer and are suffering the agonies of it until they die. To refuse to initiate a proven test regime as operated in other European countries is not just illogical it is brutally inhumane. Alternatives comment: “Could be”. What is that supposed to mean ? Other comments: Make sure review panels are representative
P191	Discussion comment: I consider that the decision not to screen black men and men with a family history of prostate cancer is wrong. It runs contrary to the Government’s professed shift in its NHS 10 Year Plan to move from treatment to prevention. The cost of introducing such screening would be more than covered by the savings in treatment costs associated with later stage diagnosis. By all means proceed with further research, but do not use this as a reason for delaying the introduction of routine screening for black men and those with a family history. Recommendation comment: See comments above. Alternatives comment: Promote and fund the use of non invasive treatments for prostate cancer.

Affected Comment:

Yes, I had advanced prostate cancer, Gleason 9 as I later found out

Like nearly every man, I had no symptoms at all before I was diagnosed, which was because my identical twin brother was diagnosed. But only because he had symptoms of the cancer in other areas of his body (bones and liver). They were prostate cancer cells that had metasized

He died ***** years ago, no treatment could save him

So as someone genetically identical, I was tested and diagnosed, I had an immediate radical prostate removal

That is the only reason I am alive today

There had been no diagnosed prostate cancer in the men in my family. And also no history of breast cancer

So why would I have thought to be tested, particularly when the test isn't available from the NHS

In my brothers quest for treatments to save his life, he was eventually diagnosed with having the BRCA 2 defective gene.

But once again he would never have been tested for it if he hadn't had terminal prostate cancer

Why would anybody have been tested?

I am now ***** now and the gene hadn't even been discovered in my fathers generation

So I could have had no inkling of the fact I might have it

I do know that the combination of the PSA and DRE aren't conclusive but they are the best we have now

Evidence Comment:

I believe that the sample size was too small, particularly for black men (I am white by the way)

I also believe that insufficient weight was given to the fact that previous generations would almost certainly not have been tested for prostate cancer

So the chances of someone of my generation having been tested via PSA would be negligible, and the advanced knowledge of family history and of having the BRACA gene would have been vanishingly unlikely

I have some incontinence problems, and some impotence ones. But I am alive

I'd take that any day

Discussion comment:

Unfortunately this is yet another example of the government putting short term savings ahead of long term costs

	The report talks about the cost of MRI and Biopsy but ignores the fact that most false positives would have been screened out by that stage Even the costs of the MRI and biopsy are insignificant compared with the cost of treatment And the cost of the PSA blood tests and DRE examinations are trivial In particular the conclusion not to screen men who have a family history of prostate cancer (not just any cancer) is wrong and not justified by either costs or the outcomes of treatment in time to save lives Recommendation comment: Yes I do Not for anyone, but for men with family histories of prostate cancer. Or breast cancer since the two are strongly linked, particularly if the man has the BRACA 2 gene defect And once again, the share of the population of my generation who would have been tested for those two conditions is negligible, so it's wrong to use just that as a screen As I've said, the cost of PSA plus DRE is very small, so that should be the screen to determine whether any further tests should be done Every man with any actual or suspected family history should be entitled to be tested. And any man who has the symptoms should be tested for the BRACA 2 gene The cost of that BRACA test is reducing exponentially and that trend will continue Alternatives comment: Can't do it The NHS can't know if someone has an elevated risk of having prostate cancer until the man has some symptoms, which are typically only when the cancer has spread. So it's the symptoms of incurable cancer that gets the patient diagnosed in the first place By which time it is very often too late to save their life It is a primary example of the government (not the NHS as it's a funding issue) placing short term cost savings over long term costs of treatment The tests should be properly funded, and not by the usual government device of announcing funding while at the same time saying (in the small print) that they are not actually giving any more money, but that the NHS needs to find the money from reduced spending in other areas the Other comments: The government – particularly Wes Streeting the minister responsible for health – this week anyway, should pay much more attention to the consequences of not funding cheap tests that could save so many lives in the medium term

P193	Affected Comment: I have Prostate Cancer as has my ***** Discussion comment: Yes it is clear that the existing system has not succeeded in either being fair across the UK or in our area, served by *****. Trust has lead to a lower stage 4 result The current clear north south divide will not be resolved by suggesting using Brac 1 &2 genetic testing to allow the recommendation of a PSA test. Clearly the existing system, patient driven, disadvantages a significant part of the adult male population. Recommendation comment: Whilst the PSA test may not be a clear marker of the presence of treatable cancer it is the best we have. However subsequent tests have become state of art. MRI, CT, Bone Scans, Biopsy trans perineal under ultrasound guidance undertaken by highly trained professionals are safe. Leading onto PET scans prior to treatment. Alternatives comment: All alternatives will continue to be too late for many. Early diagnosis is critical to reducing stage 4 & 5 with cost savings and positive outcomes. Other comments: This proposal will do nothing to reduce treatable later onset prostate cancer. It will require genetic testing of thousands of people. GP's in discussions with patients should be able to recommend a test with appropriate follow up.

P194	Affected Comment: Yes husband, and his ***** initially diagnosed with significant rise in psa and confirmed with biopsy. We have many friends who also have ca prostate, some of these symptomatic, some who asked initially for psa following publicity of condition or urged by family or friends. Discussion comment: Very disappointed in review outcome particularly in view of family history. Brother also had ca breast but husband refused any DNA testing. So Results of Brac-1 and 2 unobtainable. Yes Recommendation comment: Screening should be recommended. If psa is significantly raised further imaging MRI or. Bx can follow, the latter is now far less likely to cause infection than previously as now normally performed trans perineally. The request for psa is much more likely to come from educated/informed men, denying others the chance of early diagnosis as their gps are not allowed to offer the test. Alternatives comment: Well psa is not a marvellous test but the best available at the moment and could help to reduce risk of cancer being untreatable. Rectal examination is fairly useless and has put men off from getting diagnosed Other comments: Genetic testing as a preliminary test (Brac -1 and2) is not a useful investigation Psa is cheap and cheerful and should be offered with full explanation that if raised further testing would be advised
P195	Affected Comment: Yes – at least two close friends Evidence Comment: The evidence from Sweden and Norway (and, to a lesser extent, Germany). The population there includes fewer men in high risk groups, particularly black men. Despite this, they have a screening programme that includes MRI and risk stratification. A raised PSA does not lead straight to biopsy. Nor does it in the UK, for that matter, As such, it's hard to believe that the risks still outweigh the benefits. Recommendation comment: Yes – the current recommendation seems to be based on previous practice in the NHS where biopsy was used early for those with raised PSA. That is no longer so. Furthermore, the risk/benefit ratio is improving as technology develops. Alternatives comment:

	Most men over 65 could get a PSA by going to their GP. This could be recommended to all over 65 males.
P196	Affected Comment: As a ***** man, this year I have struggled to get investigated for potential prostate cancer after having some urinary symptoms. At the time I felt afraid and then like I was a burden to the NHS – I shouldn't have been left with these feelings. It could impact on my likelihood to seek medical attention again. Recommendation comment: Screening has to be viewed as positive if it raises the issue and gets just a proportion of men to be checked out. Screening would support men who feel stigmatised and afraid of seeking medical attention to reach out. A sensible screening programme should not mean unnecessary biopsies if the process is right – with PSA and then MRI first. Early diagnosis would ultimately save the NHS money – not to mention save the patient from undergoing extensive pain and anguish whilst going through late stage treatment. Is there not a question of equality with breast screening for women to be asked? Alternatives comment: There should be a comprehensive comms/media campaign – whether there is a screening programme or not – but ideally to support a screening programme. Other comments: Use of the neighbourhood model to promote any screening/comms programme.

	Recognise the importance of primary care in men's health – prostate cancer screening should be part of a 'well mans' screening service provided through primary care – to cover a range of different illnesses and/or diseases.

P197	Affected Comment: Having early retired and being pretty fit the diagnosis was a big shock to my family. I'm living with prostate cancer, I live an active life but it's always there in the background – apart from the need to urinate regularly, have ED- I am pretty fit. Being of a stoic disposition it doesnt affect me mentally much. History:- ***** I was diagnosed with ***** prostate cancer after a routine 'healthy man' clinic at my local GP surgery when I had a blood test. I had no symptoms. I had a prostatectomy in *****. As my PSA was rising I had some Radiotherapy ***** later. I had annual psa blood checks & as the PSA was rising in ***** I had a CT scan which showed the cancer had spread. I then had chemotherapy. I'm now have ***** hormone injections & an annual blood test. When my psa gets to 4 (as of ***** it is ***** and rising) my Oncologist says I will need some more chemotherapy. Evidence Comment: Nothing to add. Discussion comment: I believe routine blood checks for men aged 50+ plus those in at risk – should be available annually. Recommendation comment: Yes. As above. I did not have symptoms but I still had cancer. Alternatives comment: Don't know ? Other comments: None.

Affected Comment:

I was diagnosed with prostate cancer in ***** just after my ***** birthday. I'd had regular PSA tests since ***** and a slight change in my ***** test alerted my GP who referred me for further investigation.

I had no symptoms.

Thanks to PSA testing my cancer was diagnosed at stage 1 and treated with low dose brachytherapy. Treatment was necessary as some of the biopsy samples found were deemed to be aggressive. I am now ***** years cancer free although I still have an annual PSA tests.

I was told I would have got into my ***** before symptoms presented themselves.

Discussion comment:

We have a dilemma here. I fully understand the scientific approach of 'more information needed' before screening can be recommended. However, it may be many years before screening methods are deemed to be more accurate.

The PSA test can be the first indicator that a man with no symptoms has prostate cancer which can be cured (my situation as described above). No one disputes this fact.

My concern is that the recommendations will cause fewer men to pursue their 'right' to a PSA tests from 50.

We still need to ensure that man (and women) are aware of the test and should be encouraged to discuss its pros and cons with health care professionals especially if they are in a high risk group by ethnicity or family history (my older brother died from prostate cancer *****).

Education is key here and some men are difficult to reach.

Recommendation comment:

I think screening should be considered for high risk men from an Afro Caribbean heritage and men with a family history of the cancer.

Alternatives comment:

I think men from an Afro Caribbean background should be offered the PSA test (after consultation on the pros and cons) from the age of 45 or even 40.

P199	Affected Comment: Only my grandfather Evidence Comment: No Discussion comment: I believe there is enough evidence for screening if we look to our European neighbours, we don't need to delay this with unnecessary further studies. Recommendation comment: Yes screening should be recommended, to save lives and save NHS money in expensive surgery radiotherapy treatment. Alternatives comment: Really for those potential patients at risk with family history or black men there is no great alternatives in my opinion. Other comments: stop procrastinating and implement the screening.
P200	Affected Comment: As cancer has affected at least three members of my family, I am naturally concerned. I have been fortunate that my doctor referred me to the hospital and whilst they have confirmed that it is a benign enlarged prostate. They do not think that I will get cancer although I am suffering from the problems associated with prostate problems. Even so, the GP's are hesitant to give me a regular PSA test (probably to reduce their costs), this does not stop me from worrying. All men should be offered a regular annual test. Even though it is not accurate, it is better than nothing and can pick up the problem before it becomes an expensive medical procedure. To say that it will only be offered to men with a certain gene is ridiculous, how is someone to know if they have this additional aspect that means they should have a PSA? As this is the last cancerous problem without regular testing seems to denot a government that does not care about men above 40! Evidence Comment: See above Discussion comment: See above. Recommendation comment: Definately recommend, see above Alternatives comment:

	Spend money on more research to find an accurate test to replace PSA.

P201	Affected Comment: Yes, I, and other relatives. have all prostate cancer related issues. Further degrees of relatives and friends also affected. None found by NHS screening, some stage 4, some now dead. All missed, just for the sake of a ten pound test. I have submitted an earlier letter to your secretariat, which I hope you take time to read. Evidence Comment: The UK NSC review demonstrates a reasonably complete approach, drawing on major recent trials and modelling work, but several substantive concerns emerge about gaps and emphasis in the evidence base. The review relies heavily on large population data and cost-effectiveness models, yet key areas lack either direct evidence or are hampered by uncertainty that could have been more actively addressed. Firstly, there is a notable scarcity of high-quality, direct evidence specifically for Black men and those with a family history, despite these groups being at markedly higher risk and a focal point for policy decisions. Evidence from major trials is extrapolated to these groups, primarily relying on assumptions or secondary analyses, rather than primary stratified outcomes. This weakens the reliability of any assertions around relative harms and benefits and adds uncertainty. Secondly, the review appears to adopt an overly cautious threshold for benefit in certain groups (especially Black men and those with family history), while simultaneously expressing greater confidence in the recommendation for BRCA carriers. This asymmetry partly arises from limitations in available data, but the application of different standards to risk groups risks introducing inconsistency and deliberately minimising the importance of equity and targeted improvement. Thirdly, the evaluation should more robustly address emerging innovations and real-world service issues – such as the advancing adoption of MRI-based diagnostic pathways, genetic risk scoring, and dynamic patient engagement models – which are only briefly acknowledged as next steps rather than critically interrogated within the current evidence assessment. These developments may dramatically shift both the risk–benefit balance and acceptability of future screening, yet this is markedly underplayed in the main policy narrative and recommendations. Finally, there are missed opportunities to synthesise UK audit data, service-user perspectives, and learnings from recent pilot, EU or regional risk-stratified initiatives, which could provide supplementary real-world context to fill persistent evidence gaps left by randomised trials. These perspectives would be valuable to strengthen both conclusions and confidence in implementation options. In short it falls short of an acceptable standard for a topic of this seriousness and complexity. Discussion comment: The discussion, conclusion and recommendation sections are reasonable within their own framing, but they embed several important tensions and omissions that merit comment. Framing of uncertainty and consistency – The review acknowledges substantial uncertainty in the natural history parameters and in data for Black men and those with family history, yet this uncertainty is applied asymmetrically. For BRCA carriers, similar or greater structural uncertainties (no BRCA-specific treatment or utility data, reliance on general-population parameters) are accepted as compatible with a positive recommendation, whereas for Black men and family-history groups uncertainty is treated as a reason to withhold even a conditional

or evaluative offer. This creates an implicit double standard that is not fully explored or explained in the discussion.

Interpretation of cost-effectiveness – The conclusions lean heavily on the statement that screening for Black men and those with family history is “uncertain” or “unlikely to be cost-effective” at a £20,000 per QALY threshold, but the discussion does not transparently explain that for some Black-men scenarios the incremental net monetary benefit is positive with high probability under plausible uptake assumptions. Nor does it engage with the normative question of whether, for small high-risk populations with marked inequities, a slightly lower cost-effectiveness threshold should be decisive, or whether equity and burden-of-disease arguments should carry more weight.

Underplaying of equity and existing practice – The recommendation to maintain an “against” stance for Black men and family-history groups does not fully deal with the reality that these men are already being tested opportunistically, with unstructured harms and benefits. The discussion frames screening mainly as the introduction of new harms – which isn’t the case, rather than as a potential way to rationalise and improve an already existing, inequitable testing landscape. Equity is acknowledged but remains peripheral to any of the core recommendation logic.

Relationship to TRANSFORM and future evidence – The review positions TRANSFORM as the route to resolving uncertainty, especially for Black men, but the conclusion does not consider recommending interim, tightly evaluated targeted offers that could run in parallel and feed into that evidence base. This makes the recommendation more static than it needs to be and risks several further years of avoidable late-stage diagnoses in the highest-risk groups. This is unacceptable.

Communication of harms and modern pathways – The discussion imports high overdiagnosis and overtreatment penalties from historic trials and models but only briefly acknowledges modern MRI-led pathways, improved active surveillance and shared decision-making. The recommendation therefore reflects a worst-case interpretation of harms without fully considering what a deliberately optimised pathway for high-risk men might achieve.

Overall, the conclusion and recommendation are internally consistent but unduly conservative. They under-utilise positive signals from the modelling for Black men, apply caution unevenly across risk groups, and do not sufficiently integrate equity, current opportunistic practice, or realistic pathway optimisation into the decision narrative.

Recommendation comment:

Screening should be recommended – in a targeted, evaluated form – because the review itself shows that failing to detect aggressive disease early causes substantial, avoidable harm, and because a BRCA-only approach leaves many high-risk men unprotected and unaware of their risk.

The narrative describes how men diagnosed late, particularly with metastatic disease, experience severe pain, fractures, spinal cord compression and complex multi-modality treatment, with marked and lasting loss of quality of life.

Under existing opportunistic testing many high-risk men are not being picked up in time. The SCHARR model is explicit that the primary benefit of screening is a stage shift, preventing some of these late, high-morbidity presentations by diagnosing earlier-stage disease. Against this, harms in the model are largely treatment-related and concentrated among men who would not otherwise have died of prostate cancer; but those harms also arise today under unstructured

opportunistic PSA testing, without any systematic attempt to direct testing towards those at greatest risk.

Within the review's own framework, BRCA-carrier screening is endorsed because cancers in this group are more aggressive and earlier, making the balance of benefit to harm clearly favourable even with acknowledged data gaps. However, the model assumes that knowledge of BRCA status increases with age and recognises that many men with pathogenic variants are currently unaware of their status. Those men will not benefit from a "BRCA-only" recommendation, because they will never be identified to enter the programme. At the same time, Black men and men with family history are known to have substantially higher baseline risk, yet the draft recommendation is "against" screening these groups, despite modelled scenarios for Black men showing positive or near-neutral net benefit and notable mortality reduction under plausible strategies.

Taking these elements together, the internal logic of the review supports saying "yes" to targeted screening, not only for known BRCA carriers but also, at minimum, for clearly defined higher-risk groups such as Black men and those with strong family histories, within a tightly evaluated programme.

This approach would: reduce the current burden of late-stage, high-harm disease; replace uncontrolled opportunistic testing with structured pathways that actively minimise overdiagnosis; and partially mitigate the fact that many genetically high-risk men are unaware of their BRCA status.

A cautious, risk-stratified "yes" is therefore more consistent with the harms described in men who miss early detection, and with the review's own acceptance of uncertainty when the potential benefits for a high-risk group are substantial.

As it stands, the recommendation does not go far enough and legal action is likely against GPs and medics who knowingly refuse to test, or actively delay testing, or recommend structures aimed at delaying presentation of men until metastatic disease presents across all 3 groups. Therefore, this review needs to deliver a more complete solution, in parallel with Transform reporting.

Alternatives comment:

Several alternatives to a formal PSA screening programme are visible within the review and could be strengthened or scaled now without waiting for TRANSFORM results.

Optimise current diagnostic pathways – The review recognises that MRI-based assessment and improved biopsy techniques can better distinguish aggressive from indolent cancers, potentially reducing overdiagnosis and overtreatment. NHS policy could prioritise universal access to high-quality MRI-led diagnostic pathways for any man with raised PSA or concerning symptoms, with clear standards on imaging quality, reporting and targeted biopsy.

Improve opportunistic testing and decision support – At present, many men are tested opportunistically, without consistent information or risk assessment. The NHS could:

- * Standardise GP guidance and decision aids so that men, especially those from high-risk groups, receive balanced information on benefits and harms when requesting or being offered a PSA test.

* Embed simple, structured risk prompts in primary care systems (age, ethnicity, family history) to support more rational, equity-orientated case-finding without calling it “screening” – perhaps call it risk assessment.

* Strengthen risk assessment and genetic services – The review highlights BRCA-related risk but notes that many carriers are unaware of their status and that BRCA data are applied using general-population treatment and utility assumptions. Government could invest in:

* Better identification and referral of families with clustering of prostate, breast and ovarian cancers, including primary-care tools to trigger genetic referral.

* Capacity in genetic counselling and testing, so that more at-risk men know their status and can access targeted surveillance pathways, even outside a formal screening programme.

Focus on equity, access and early diagnosis – Black men and those with family history have higher baseline risk but face data gaps and later presentation. Targeted community programmes could:

* Raise awareness of symptoms and familial risk in Black communities and high-risk families.

* Improve access to timely urology assessment for men with raised PSA or symptoms, with explicit monitoring of stage at diagnosis and time to treatment by ethnicity and deprivation.

Invest in research and learning health systems – The review already anchors future progress in TRANSFORM and points to the need for better natural-history data, especially in Black men. Alongside TRANSFORM, NHS and government could:

* Use national audits and cancer registries to continuously track patterns of presentation, stage, treatment and outcomes, feeding back into service improvement.

* Support pragmatic pilots of risk-stratified case-finding pathways within usual care, with built-in evaluation of quality of life, overdiagnosis and resource use.

Together, these alternatives would help people with or at risk of prostate cancer by improving timely diagnosis and treatment quality, even in the absence of, or alongside, a formal organised screening programme.

Other comments:

Yes. Several additional recommendations follow logically from the review and would complement any decision on formal screening.

Make equity an explicit decision criterion -The review repeatedly notes higher risk and later presentation in Black men and men with family history, yet equity is treated as background rather than a formal part of the decision rule.

Future NSC deliberations should explicitly weight reduction of inequalities alongside cost-effectiveness, particularly for small, clearly high-risk subgroups.

Treat Black and family-history groups as “evaluation priorities” – Given that risk-stratified strategies for Black men show positive or near-neutral net benefit with meaningful mortality reduction in several scenarios, these groups should be designated as priorities for pragmatic, evaluated implementation rather than excluded until TRANSFORM reports.

The NSC could invite proposals for time-limited pilot programmes using modern MRI-led pathways, with embedded outcome and overdiagnosis monitoring.

Tighten and standardise opportunistic practice – The review highlights current harms – imagined or otherwise – from unstructured PSA use and invasive diagnostics but does not set out a national standard for opportunistic testing. NHS England and the devolved nations should:

- * Issue a unified, plain-language decision aid for men considering PSA.
- * Define minimum pathway standards (MRI first, targeted biopsy, strong active surveillance) wherever PSA is offered, to reduce avoidable treatment harms.
- * Accelerate BRCA and familial risk identification – Because the model assumes many BRCA carriers are currently unaware of their status, a BRCA-only screening recommendation must be coupled with more systematic identification of at-risk families. The NHS should strengthen familial-risk prompts in primary care, referral criteria for genetics, and capacity in genetic counselling and testing.
- * Improve transparency and stakeholder engagement around modelling – SCHARR emphasises that overdiagnosis is model-dependent and that results are sensitive to structural choices and discounting assumptions. The NSC should make model code and key assumptions more openly accessible to independent academic and public scrutiny and involve advocates and high-risk communities directly in discussing acceptable trade-offs.

Use TRANSFORM as part of a learning system, not a pause button -

The review positions TRANSFORM as the main route to better tests and evidence, but the NSC could frame it within a broader learning-health-system approach: linking trial data, national audit, and evaluated service changes so that policy can be iteratively updated rather than revisited only at long intervals.

In short, and here's the personal appeal – don't let my son have to find out the way I did. Leave a legacy from your work which demonstrates fairness, equity and honesty. Focus equitably on those men who aren't given a chance at longer life, by dint of a deliberate NSC sanctioned policy on denial of testing – there lies the real – not imagined harms. BRCA is a tiny, almost insignificant proportion of men suffering from prostate cancer – make this current review count.

True objectivity and transparency are required for this most serious matter.

Thank you for your consideration.

Addendum:

In the UK NSC's 28 November 2025 prostate cancer screening consultation, the commissioned SCHARR modelling report notes that Stockholm3 was excluded because modelling required more detailed inputs than were available from published sources and could not be accessed under the existing confidentiality/data sharing constraints.

This exclusion should not be portrayed as a lack of evidence. NICE's Medtech Innovation Briefing (MIB303) concludes that the screening evidence base for Stockholm3 is adequate, peer reviewed, and includes population based screening studies.

Stockholm3 has been evaluated in multiple screening contexts, including population invitation and repeat screening pathways with MRI, demonstrating improved identification of cancers needing treatment compared with PSA alone and the potential to reduce unnecessary scans and biopsies.

Importantly, Stockholm3 has also been prospectively validated in an ethnically and racially diverse cohort (SEPTA), supporting generalisability and equity considerations.

I would therefore request that UK NSC includes Stockholm3 in its evidence assessment and modelling, and engages with the test developers under appropriate governance so the required technical inputs can be provided for a full evaluation.

Dear UK NSC Secretariat

Many thanks to you and Prof Richards for your reply – much appreciated.

I submitted an electronic public response through the NSC website just before Christmas. Unfortunately, this was somewhat constrained by the 2500-character limit.

I work as a volunteer for several prostate charities but do not hold a staff position with any of these organizations.

The additional letter was sent as a professional courtesy and would best supplement my original electronic submission. I felt it useful to keep all parties working transparently on a level playing field.

A copy in electronic format is attached as requested.

Kind regards and best wishes to all at the NSC for 2026.

28 December 2025

Rt Hon Wes Streeting MP

Secretary of State for Health and Social Care
Department of Health and Social Care,
39 Victoria Street,
London SW1H 0EU

Dear Secretary of State,

UK National Screening Committee Prostate Cancer Decision: Request for Ministerial Intervention

I am writing to request your urgent intervention in the UK National Screening Committee's recommendation on prostate cancer screening, announced on 28 November 2025. The decision seems to rely, in part, on fundamental errors of logic and evidence that, if implemented, will cost men's lives.

This is not a letter seeking to second-guess clinical judgement. It is a letter demonstrating that the NSC has applied **different evidence standards to different groups of men** - approving screening for one high-risk group whilst rejecting others with equivalent or stronger supporting evidence. The enclosed technical analysis documents over 150 specific methodological failures across the consultation documents.

The Decision in Summary

The NSC has recommended prostate cancer screening for men with BRCA gene mutations (approximately 0.3% of men). It has simultaneously recommended against screening for Black men and men with relevant family history.

Group	Probability of Cost-Effectiveness	Trial Evidence	NSC Decision
Black men	81%	Extensive observational data	REJECTED
Family history	78-79%	Extensive observational data	REJECTED
BRCA carriers	Not modelled directly	None	APPROVED

The Logical Contradiction

The NSC justified its recommendation for BRCA carriers on the grounds that they develop more aggressive cancers. This is the precise characteristic that also defines prostate cancer in Black men - who have double the mortality rate and present with more aggressive disease. The same reasoning that justified screening BRCA carriers logically requires screening Black men. The NSC applied it to one group and not the other.

Equality Act Implications

The differential treatment of Black men may also raise questions under equality legislation. The decision to approve screening for a predominantly white genetic subgroup whilst rejecting screening for a racial group with stronger modelling evidence requires objective justification. The NSC has not provided any.

What I Am Asking You To Do

1. Extend the consultation period to allow proper scrutiny of the methodological failures.
2. Commission an independent review of the SCHARR modelling framework.
3. Require the NSC to explain the evidential basis for applying different evidence standards.
4. Extend the screening recommendation to include Black men and men with relevant family history.

Yours sincerely,

Enclosures: Consolidated Document Analysis (150+ issues documented) and Cross Reference Scheme

cc: Chief Medical Officers; Chair, UK National Screening Committee (plus additional Critical Analysis document); Pete Wishart MP, Jenny Minto MSP

CONSOLIDATED DOCUMENT ANALYSIS

UK National Screening Committee Prostate Cancer Screening Consultation
February 2026

EXECUTIVE SUMMARY

This consolidated report presents findings from detailed technical analysis of four key documents underpinning the UK National Screening Committee's draft recommendations on prostate cancer screening. The analysis reveals systematic methodological shortcomings, factual errors, internal inconsistencies, and critical omissions. **Total issues identified: 150+**

PART 1: SCHARR PHASE 3 MODELLING REPORT

1.1 Model Structure and Assumptions

Issue 1.1.1: Reliance on CAP trial data. 'The model's screening arm was designed to reflect the CAP trial protocol... men aged 50 to 69 years from participating general practices were randomised.'

Issue 1.1.2: PSA threshold not adequately explored. 'Men with PSA levels ≥ 3.0 ng/mL were offered a standard 10-core transrectal ultrasound-guided biopsy.'

Issue 1.1.3: Markov cohort structure limits granularity. 'The model made a pragmatic assumption that cancers would progress sequentially from stage 1 through to stage 4. In reality, this is not fully understood.'

Issue 1.1.4: 'Once screened, always screened' assumption unrealistic. 'The model applies flat uptake rate; future model development should incorporate variable uptake based on results of the previous screening decisions.' (SCHARR Section 10.3, p.180)

1.2 Time Horizon and Discounting

Issue 1.2.1: Effective horizon truncates mortality benefits. 'An assumption was made that if someone was still alive 15 years after being diagnosed with prostate cancer, then they would not die from the disease.'

Issue 1.2.2: Sensitivity analysis produces same conclusion. 'Using this assumption instead of extrapolating mortality over a lifetime (70 years) had only a small impact on cost-effectiveness.'

Issue 1.2.3: Asymmetric capture of harms vs benefits. 'Harms can arise as early as 2 weeks after beginning treatment, and can persist for a very long time (6 years or more, or possibly a lifetime).'

Issue 1.2.4: No sensitivity analysis on time horizon itself. Time horizon sensitivity not reported in main results tables; fixed at 15 years post-diagnosis assumption.

1.3 Diagnostic Pathway

Issue 1.3.1: Model includes MRI but parameters from PSA-biopsy era. 'As mpMRI was not part of the CAP trial protocol, the model similarly assumed that all men with elevated PSA levels underwent biopsy directly.'

Issue 1.3.2: Systematic overstatement of diagnostic harms. 'As no data were identified describing variation in mpMRI sensitivity by stage or grade, uniform sensitivity was assumed across all cancers.'

Issue 1.3.3: Biopsy complications from transrectal era. 'Although the CAP trial used TRUS, the current model uses LATP biopsy. To reconcile this difference, biopsy accuracy in the model was adjusted.'

Issue 1.3.4: MRI sensitivity/specificity data incomplete. 'Sensitivity and specificity values for mpMRI and biopsy were based on Ahmed et al. (2017). As no data were identified describing variation in mpMRI sensitivity by stage or grade, uniform sensitivity was assumed.'

1.4 Treatment Patterns

Issue 1.4.1: Treatment parameters based on pre-active surveillance era. 'More than half of men who initially start on an active surveillance pathway will move onto having radical treatments (surgery or radiotherapy) over 15 years.'

Issue 1.4.2: Treatment harms from older surgery. 'At 6 years after treatment, 36-50% men having radical treatments will have erectile problems, 5-13% will be incontinent of urine.'

Issue 1.4.3: Active surveillance QoL not properly valued. 'Those who do not receive treatment but are under active surveillance may also feel distressed by the impression that they have an untreated cancer.'

Issue 1.4.4: No active surveillance progression data. 'A limitation to using EQ-5D is that the connection between these 5 domains and the benefits and harms we see in screening is not always obvious or explicit.'

Issue 1.4.5: Treatment pathway assumed identical. 'The treatment pathway was modelled to be the same under usual care and in each screening strategy.'

1.5 Risk Stratification

Issue 1.5.1: Risk stratification bolted on, not foundational. Model originally designed for population screening; risk stratification added as secondary analysis rather than core architecture.

Issue 1.5.2: Combined risk factors not modelled. 'There was inconsistency... because of no data describing three-factors correlations: BRCA carrier, familial risk, and ethnicity.' (SCHARR Section 10.3, p.179)

Issue 1.5.3: Family history definition too broad. 'Men with a family history of prostate, breast, or ovarian cancer make up about a third of all men.'

Issue 1.5.4: No subgroup analyses for Black men. 'There is a clear need for UK-specific data on the Black population, particularly regarding GGG distribution by age at diagnosis, stage at diagnosis by age.'

1.6 Calibration and Validation

Issue 1.6.1: Acknowledged calibration limitation. 'The model predicted prostate cancer deaths as a proportion of those diagnosed in the non-screening arm, higher than in the CAP data.'

Issue 1.6.2: Calibration against contaminated baseline. 'Due to the uncertainty around how much PSA testing of asymptomatic men is happening in current practice, it is difficult to clearly understand what and how much change to PSA testing practice.'

Issue 1.6.3: Model calibration limitations acknowledged. 'Calibration results showed that the NHD parameters were split across several distinct regions of parameter space, what impacted probabilistic results.'

1.7 Overdiagnosis Estimation

Issue 1.7.1: Circular reasoning. 'Overdiagnosis is a model-dependent construct rather than a directly observable outcome.' (SCHARR Section 10.2.2, p.178)

Issue 1.7.2: Overdiagnosis rates at upper end. 'Estimates of overdiagnosis varied widely (6-82%), both across and within models.'

Issue 1.7.3: Rates not adjusted for MRI pathway. MRI pathway expected to reduce detection of clinically insignificant cancers but model parameters from pre-MRI era.

Issue 1.7.4: Overdiagnosis conflated with overtreatment. 'Screening in BRCA carriers led to substantial overdiagnosis, ranging from 13% with a single screen at age 45 to 79% at age 72' [includes men on AS].

PART 2: NSC EVIDENCE REVIEW COVERSHEET

2.1 Inconsistent Evidence Standards

Issue 2.1.1: BRCA recommended despite 'no data' for BRCA population. 'There are no data on prostate cancer screening, diagnosis, and treatment in the BRCA population.'

Issue 2.1.2: 81% probability deemed insufficient. 'This strategy was cost-effective at the £20,000/QALY threshold in 81% of runs' [Black men] but deemed uncertain.

Issue 2.1.3: Aggressive cancer rationale applied selectively. 'Men with a BRCA gene variant are more likely to develop faster growing and aggressive cancers at an earlier age' [same modelled for Black men].

Issue 2.1.4: Trial evidence demanded for Black men only. 'There is a lack of strong evidence from large trials about the balance of harms and benefits for this group of men' [Black men only].

Issue 2.1.5: IMPACT trial not cited. Relevant prospective data from IMPACT study on BRCA carrier screening not discussed in consultation documents.

2.2 Missing Documentation

Issue 2.2.1: No equality impact assessment. No published Equality Impact Assessment accompanying consultation despite differential recommendations by ethnicity.

Issue 2.2.2: No BRCA implementation plan. 'Importantly, not all men with a BRCA1/2 gene mutation may know they have one... there has been a rapid rise in genetic testing in recent years and the model is therefore likely to underestimate.'

Issue 2.2.3: BRCA testing cost-effectiveness not evaluated. 'This study did not look at whether testing for the BRCA gene itself is cost-effective—that would require separate research.'

Issue 2.2.4: No cost-effectiveness threshold stated. 'There is ongoing debate about what WTP threshold is most appropriate for screening programmes.'

2.3 Uptake Assumptions

Issue 2.3.1: Perfect uptake for BRCA; realistic 36% for others. 'Both single and repeat screening scenarios with perfect uptake had a 100% probability of being cost effective for BRCA carriers.'

Issue 2.3.2: 36% uptake from CAP inappropriate. 'The model assumed the base case... uptake of prostate cancer screening to be 36%, based on data from the UK CAP Trial.'

2.4 Factual Errors and Omissions

Issue 2.4.1: States only Lithuania has national screening. 'Lithuania appears to be the only country with a national approach to offering PSA-based early detection.'

Issue 2.4.2: Overdiagnosis highlighted for Black men but omitted for BRCA. 'About 44% of prostate cancers detected would be overdiagnosed' [Black men] but BRCA overdiagnosis 13-79% not highlighted.

Issue 2.4.3: Mortality benefit for Black men understated. 'Over a 15-year period, an additional 571 prostate cancers would be detected and around 7 to 11 deaths prevented.'

Issue 2.4.4: TRANSFORM framing misleading. 'The TRANSFORM trial anticipates that it will be able to share data in the next three years.'

Issue 2.4.5: Per-person mortality reduction for Black men not stated. Black men have 2-3x higher baseline mortality; proportional benefits greater but absolute terms not emphasised.

Issue 2.4.6: Number needed to screen comparison not provided. No comparison of NNS with breast, bowel, cervical screening programmes to contextualise findings.

Issue 2.4.7: PROFILE study findings not discussed. PROFILE study data on high-risk men not incorporated into consultation analysis.

PART 3: EVIDENCE REVIEW NARRATIVE

3.1 Outdated Data Sources

Issue 3.1.1: States PCPT 'more than ten years old' when actually 20+ years. 'The amount of PSA in the blood across the population was drawn from data from a US screening trial (the PCPT Trial). Though these data are more than ten years old.'

Issue 3.1.2: CAP 36% uptake inappropriate for national programme. 'The model assumed the base case... uptake of prostate cancer screening to be 36%, based on data from the UK CAP Trial.'

Issue 3.1.3: Cost year 2022/23 but clinical parameters older. 'All costs were reported in pounds sterling for the year 2022/23' but clinical parameters from older sources.

3.2 Statistical Errors and Inconsistencies

Issue 3.2.1: 78.9% 10-year survival conflates overall with cancer-specific. 'Nearly 8-in-10 people (78.9%) diagnosed with prostate cancer survive for 10 or more years after their diagnosis.'

Issue 3.2.2: False positive rate inconsistent. 'Around three quarters (72%) of people with a raised PSA do not have prostate cancer' vs '61-72% of people with a raised PSA level.'

Issue 3.2.3: Treatment harms: 66% ED at 6mo vs 36-50% at 6yr. '66% (two thirds) will experience moderate or severe erectile dysfunction' [6 months] vs '36-50% men having radical treatments will have erectile problems' [6 years].

Issue 3.2.4: Family history definition captures ~1/3 of men. 'A family history was taken to mean any first-degree relative with breast, ovarian or prostate cancer... This sub-group included about one-third of all men.'

Issue 3.2.5: AS conversion 'more than half' at 15yr. 'More than half of men who initially start on an active surveillance pathway will move onto having radical treatments (surgery or radiotherapy) over 15 years.'

3.3 Systematic Harm Emphasis

Issue 3.3.1: Linguistic asymmetry. 'Screening can be beneficial' vs 'The most common lifelong harms associated with surgery include urinary incontinence.'

Issue 3.3.2: Structural ordering places harms before benefits. Document structure places detailed harm descriptions before benefit discussion in Section 2.

Issue 3.3.3: Harms enumerated with percentages; benefits described generally. '71% (nearly three quarters) will find it difficult to control their bladder' vs benefits described without equivalent specificity.

Issue 3.3.4: No 'what if we don't screen' scenario. Document does not present counterfactual scenario of consequences of not screening high-risk men.

Issue 3.3.5: Emotive language for harms; neutral for benefits. 'Severe pain, fractures, or spinal cord compression' described emotively; mortality benefit reduction described neutrally.

Issue 3.3.6: '80% would not benefit' ignores AS recipients. 'The majority of men (c.80%) whose prostate cancers are identified through screening would not benefit in terms of preventing prostate cancer deaths.'

3.4 Evidence Gaps and Omissions

Issue 3.4.1: No UK-specific data on Black men. 'This assumption was informed by US-based data, as no equivalent UK data were identified.'

Issue 3.4.2: No GRADE ratings. Evidence quality ratings (GRADE or similar) not provided for key model inputs.

Issue 3.4.3: No patient preferences data. Patient preference data for screening trade-offs not incorporated into model.

Issue 3.4.4: No international comparison. Limited comparison with outcomes from countries with organised prostate screening programmes.

Issue 3.4.5: BRCA 'more conclusive'; Black men 'great uncertainty'—not quantified. 'The model is more conclusive about the balance of benefits and harms compared to cost of screening men with a known BRCA1/2 gene mutation' vs 'great deal of uncertainty' for Black men.

Issue 3.4.6: No combined risk factor analysis. 'There was inconsistency... because of no data describing three-factors correlations.'

Issue 3.4.7: No comparison with other NHS interventions. No contextualisation of cost per QALY against other NHS-funded interventions.

Issue 3.4.8: No discussion of current opportunistic testing harms. 'Current PSA testing practice is an area of high uncertainty within the model.'

3.5 Logical Failures

Issue 3.5.1: Ecological fallacy. Population-level overdiagnosis rates presented without guidance on individual risk assessment.

Issue 3.5.2: Circular reasoning in overdiagnosis estimates. 'Overdiagnosis is a model-dependent construct rather than a directly observable outcome.'

Issue 3.5.3: WTP threshold debate acknowledged but £20,000 used without sensitivity. 'There is ongoing debate about what WTP threshold is most appropriate for screening programmes.'

Issue 3.5.4: Lead time bias acknowledged but not addressed. Lead time effects acknowledged but results presented without adjustment for comparison.

Issue 3.5.5: Model designed for 'screen all men' applied to 'which groups benefit'. Model architecture designed for population screening question applied to risk-stratified question.

Issue 3.5.6: Same limitations cited against Black men but ignored for BRCA. 'There is still too much uncertainty over the benefits and harms' [Black men] but BRCA recommended despite 'no data'.

PART 4: CRUK/NSC INFOGRAPHIC

4.1 Data Source Problems

Issue 4.1.1: Combines incompatible studies. 'Based on the Göteborg II screening study... deaths prevented in men aged 50-69 from the CAP screening trial... and in men aged 55-69 from the ERSPC screening trial.'

Issue 4.1.2: Temporal mismatch. Different follow-up periods combined: Göteborg-2 (4 years), CAP (15 years), ERSPC (23 years), ProtecT (12 years).

Issue 4.1.3: Modern MRI pathway but old non-MRI mortality. Göteborg-2 MRI pathway used for diagnosis but CAP/ERSPC non-MRI mortality figures.

Issue 4.1.4: Different populations/protocols combined. Swedish screening pathway applied to UK/European mortality data from different protocols.

Issue 4.1.5: Age ranges differ. 'In men aged 50-60 (Hugosson et al, NEJM 2024), deaths prevented in men aged 50-69 from the CAP screening trial... and in men aged 55-69 from the ERSPC.'

4.2 Mathematical Errors

Issue 4.2.1: Grade Group calculation error. '12% of prostate cancers will be Grade Group 3-4' of 28 diagnosed = 3.36, shown as 4.

Issue 4.2.2: 'Up to 20 overdiagnosed' based on clinical expertise. 'The estimates of people overdiagnosed and overtreated are based on a mixture of clinical expertise and the ProtecT trial.'

Issue 4.2.3: '12 overtreated' calculation opaque. Calculation method for 12 overtreated figure not transparently documented.

Issue 4.2.4: Overtreatment logic unclear. 'This number assumes that some men who switch from active surveillance to radiotherapy/surgery within 15 years did so unnecessarily.'

4.3 Visual Framing Bias

Issue 4.3.1: Visual hierarchy emphasises harms. 'Up to 20 likely overdiagnosed' prominent; 'Up to 2 lives will be saved by inviting men to screening**' with double asterisk.

Issue 4.3.2: Harms as facts; benefits with qualifiers. '**Assumes all invited men accept a PSA test' qualifier applied to benefits only.

Issue 4.3.3: 'Up to 20' and 'Up to 2' create false equivalence. Both figures use 'Up to' framing but psychological salience favours larger number.

Issue 4.3.4: Treatment harms highlighted; mortality benefit footnoted. Treatment harms box prominent; mortality benefit in footnote position.

Issue 4.3.5: Icon representation may misrepresent proportions. 28 figures shown diagnosed but scaling to harms/benefits may not be proportional.

4.4 Critical Omissions

Issue 4.4.1: No '1,000 not screened' comparator. No parallel pathway showing outcomes for 1,000 men NOT offered screening for comparison.

Issue 4.4.2: Cancer progression harms absent. Harms of NOT screening (metastatic disease, suffering, death) not shown for comparison.

Issue 4.4.3: High-risk group context missing. Figures for general population screening only; no high-risk group outcomes shown.

Issue 4.4.4: Active surveillance option not explained. Overdiagnosed men portrayed as harmed without explaining AS pathway minimises treatment.

Issue 4.4.5: Modern MRI-first pathway benefits not mentioned. MRI-first pathway reduces unnecessary biopsies but this benefit not shown.

Issue 4.4.6: QoL for AS vs treatment not distinguished. All diagnosed men grouped together regardless of AS vs treatment pathway.

Issue 4.4.7: No comparison with other screening programmes. No contextualisation against other UK screening programme statistics.

Issue 4.4.8: Methodology for key figures not explained. References cited but derivation methodology not transparent for lay readers.

PART 5: MODEL DESIGN AND INHERITED BIAS

5.1 The Wrong Question

Issue 5.1.1: Model commissioned 2010 for 'screen all men 50-70'—obsolete question. Original SCHARR model from Chilcott 2010/2013 designed for population screening question.

Issue 5.1.2: Current question fundamentally different. 2025 question about targeted screening differs fundamentally from original population screening question.

Issue 5.1.3: Population screening framing guarantees marginal findings. Model architecture designed for average-risk population dilutes findings for high-risk subgroups.

Issue 5.1.4: Model answers wrong question. Contemporary clinical practice uses risk-stratified approaches not modelled as base case.

5.2 Inherited Parameters: 2010 to 2025

Issue 5.2.1: Core architecture unchanged 15 years. Model structure retained from original development with parameter updates rather than redesign.

Issue 5.2.2: Treatment utility values from pre-AS era. 'The amount by which EQ-5D scores were reduced... following a diagnosis of prostate cancer was based on data from the 2024 NHS Cancer Quality of Life Survey.'

Issue 5.2.3: No MRI-era pathway benefits incorporated. PROMIS trial 2017 established MRI-first pathway but model parameters from pre-MRI era.

Issue 5.2.4: Same 3.5% discount rate retained. Discount rate unchanged from original model despite longer follow-up data now available.

Issue 5.2.5: 2010 PSA sensitivity assumptions retained. 'In the model, the amount of PSA in the blood across the population was drawn from data from a US screening trial (the PCPT Trial).'

Issue 5.2.6: Natural history parameters from pre-MRI era. Natural history model calibrated to data from before MRI pathway implementation.

5.3 Architectural Features Guaranteeing Negative Findings

Issue 5.3.1: Immediate harms vs distant discounted benefits. 'Harms can arise as early as 2 weeks after beginning treatment' vs benefits accruing over 15-23 years.

Issue 5.3.2: Every sensitivity analysis same result. Multiple sensitivity analyses all confirm base case finding suggesting structural determination.

Issue 5.3.3: Model confirms hypothesis rather than testing it. Sensitivity analyses confirm rather than challenge base case assumptions.

Issue 5.3.4: Deterministic shows greater benefit than probabilistic. 'This contrasts sharply with the probabilistic analysis assuming perfect uptake' - deterministic more favourable.

Issue 5.3.5: Lead time captured but mortality benefit discounted asymmetrically. Lead time bias adjustments applied but asymmetric treatment of benefits vs harms.

Issue 5.3.6: Overdiagnosis accumulated; mortality benefit discounted. Overdiagnosis counted at detection; mortality benefit discounted over projection period.

5.4 Differential Application of Limitations

Issue 5.4.1: Perfect uptake for BRCA; realistic 36% for Black men. BRCA cost-effectiveness with perfect uptake; Black men with realistic 36% CAP uptake.

Issue 5.4.2: Trial evidence cited against Black men but not BRCA. 'There is a lack of strong evidence from large trials' for Black men; BRCA has 'no data' but recommended.

Issue 5.4.3: NSC worked around limitations for BRCA only. BRCA recommendation uses perfect uptake and aggressive cancer logic not applied to Black men.

Issue 5.4.4: Identifiability double standard. BRCA identification requires genetic testing; Black ethnicity self-identified at no cost.

Issue 5.4.5: Hardest to identify group approved; easiest rejected. BRCA (requires testing, ~35% known) approved; Black men (self-identify) rejected.

Issue 5.4.6: 'Aggressive cancer' logic applied selectively. 'Men with a BRCA gene variant are more likely to develop faster growing and aggressive cancers' - same modelled for Black men but different conclusion.

5.5 Recommendations

Issue 5.5.1: Time horizon should match natural history. Model should use time horizon matching prostate cancer natural history not artificial 15-year cutoff.

Issue 5.5.2: Contemporary clinical pathway as baseline. Model should use contemporary clinical pathway as base case not historical practice.

Issue 5.5.3: Risk stratification foundational, not bolted-on. Future model should be designed for risk-stratified screening question from outset.

Issue 5.5.4: Consistent evidence standards across all groups. Same uptake assumptions and evidence standards should apply to all risk groups.

PART 6: PROCESS AND GOVERNANCE

6.1 Transparency Failures

Issue 6.1.1: Expert group identities not published. Names and affiliations of expert advisory group members not disclosed with consultation.

Issue 6.1.2: Model code not published. SCHARR model code not made available for independent review or replication.

Issue 6.1.3: Stakeholder feedback not published. Phase 1 and Phase 2 stakeholder feedback and NSC responses not published.

Issue 6.1.4: Decision-making criteria not disclosed. No stated threshold for probability of cost-effectiveness required for recommendation.

Issue 6.1.5: Conflicts of interest not published. Declaration of interests for expert group members not included in consultation documents.

6.2 Equality and Inclusion

Issue 6.2.1: No equality impact assessment. No published EIA despite differential recommendations affecting ethnic groups.

Issue 6.2.2: PSED compliance unclear. No documentation of how PSED requirements were considered in decision-making.

Issue 6.2.3: Black men disproportionately affected. Black men 2-3x higher mortality from prostate cancer but no health inequalities analysis.

Issue 6.2.4: Patient involvement in modelling unclear. 'Patient and public voice (PPV) members' involved but role in key modelling decisions unclear.

Issue 6.2.5: Documents inaccessible for lay readers. Technical documents require specialist knowledge to understand; no lay summary provided.

6.3 Consultation Process

Issue 6.3.1: Consultation over Christmas/New Year. Consultation opened late November 2025 with deadline February 2026, spanning holiday period.

Issue 6.3.2: Technical complexity limits engagement. 185-page SCHARR report and technical narrative limit public participation.

Issue 6.3.3: No plain English summary. Infographic oversimplifies; no intermediate summary for informed public engagement.

Issue 6.3.4: Infographic joint branding raises independence concerns. Joint branding with major cancer charity may lend undue authority to contested figures. Additionally, NSC chair has Trustee role at said charity—raising potential conflict of interest and lack of independence concerns.

Issue 6.3.5: Response mechanism unclear. How detailed technical critiques will be addressed in decision-making not specified.

6.4 Timing and Context

Issue 6.4.1: Announcement timed with TRANSFORM launch. Announcement timing coincided with TRANSFORM trial launch 21 November 2025.

Issue 6.4.2: High-profile patient disclosure proximity. Sir Chris Hoy announcement proximate to policy decision timing.

Issue 6.4.3: TRANSFORM designed to answer question already answered negatively. Trial commissioned to address uncertainties after negative recommendation already made.

Issue 6.4.4: 5+ year wait while recommending against screening. 'The TRANSFORM trial anticipates that it will be able to share data in the next three years.'

Issue 6.4.5: High-risk men told to wait for evidence already available. 81% probability cost-effective for Black men deemed insufficient; told to wait for TRANSFORM.

Issue 6.4.6: BRCA pathway may remove men from TRANSFORM eligibility and impact findings. Men identified through BRCA screening may become ineligible for TRANSFORM recruitment, potentially affecting trial findings.

Issue 6.4.7: Private testing surge not addressed. Negative recommendation likely to increase private testing; implications not discussed.

Issue 6.4.8: NHS 'informed choice' pathway contamination not modelled. Existing opportunistic PSA testing will contaminate TRANSFORM control arm; not addressed.

SUMMARY: ISSUES BY CATEGORY

Category	Count	Key Documents
Model Structure and Design	26	SCHARR Report, Model Design section
Data Quality and Selection	22	SCHARR, Narrative, Infographic
Inconsistent Evidence Standards	18	Coversheet, Narrative, Model Design
Framing and Presentation Bias	18	Narrative, Infographic
Evidence Gaps and Omissions	20	All Documents
Logical Failures	10	SCHARR, Narrative
Process and Governance	28	Consultation Process
Factual Errors	8	Narrative, Coversheet, Infographic
TOTAL	150+	

APPENDIX: CROSS-REFERENCED ISSUES LIST

Complete Issues with Verified Document Quotes

UK NSC Prostate Cancer Screening Consultation

Complete Cross-Referenced Issues List with Verified Document Quotes

150+ Issues Identified Across Four Consultation Documents

December 2025

Document Key:

- SCHARR = SCHARR Phase 3 Prostate Cancer Modelling Report (185 pages)
- Coversheet = UK NSC Evidence Review Coversheet (7 pages)
- Narrative = Evidence Review Narrative Document (20 pages)
- Infographic = CRUK/NSC Screening Outcomes Infographic (3 pages)

Note: Italic text in the Quote column indicates direct quotation from source documents. Non-italic text indicates paraphrased or summarised evidence.

PART 1: SCHARR PHASE 3 MODELLING REPORT

1.1-1.4: Model Structure, Time Horizon, Diagnostic Pathway, Treatment Patterns

#	Issue Description	Exact Quote / Evidence	Reference	Category
1.1.1	Reliance on CAP trial data despite acknowledged contamination and single-screening design	"The model's screening arm was designed to reflect the screening protocol used in the CAP trial... men aged 50 to 69 years from participating general practices were randomised"	SCHARR Section 7.2.1, p.81	Model Structure
1.1.2	PSA threshold (≥ 3 ng/mL) not adequately explored; different thresholds not modelled	"Men with PSA levels ≥ 3.0 ng/mL were offered a standard 10-core transrectal ultrasound-guided biopsy"	SCHARR Section 7.2.1, p.81	Model Structure
1.1.3	Markov cohort structure limits granularity for disease with variable progression	"The model made a pragmatic assumption that cancers would progress sequentially from stage 1 through to stage 4. In reality, this is not fully understood."	Narrative Section 4.5, p.13-14	Model Structure
1.1.4	"Once screened, always screened" assumption unrealistic	"The model applies flat uptake rate; future model development should incorporate variable uptake based on results of the previous screening decisions."	SCHARR Section 10.3, p.180	Model Structure
1.2.1	Effective horizon truncates mortality benefits; captures harms immediately	"An assumption was made that if someone was still alive 15 years after being diagnosed with prostate cancer, then they would not die from the disease."	Narrative Section 4.6, p.14	Time Horizon
1.2.2	Sensitivity analysis produces same conclusion—architecture drives results	"Using this assumption instead of extrapolating mortality over a lifetime (70 years) had only a small impact on cost-effectiveness."	Narrative Section 4.6, p.14	Time Horizon
1.2.3	Asymmetric capture: harms immediate, benefits discounted over decades	"Harms can arise as early as 2 weeks after beginning treatment, and can persist for a very long time (6 years or more, or possibly a lifetime)."	Narrative Section 2.2, p.4	Time Horizon
1.2.4	No sensitivity analysis on time horizon itself (20yr, 25yr, lifetime)	Time horizon sensitivity not reported in main results tables; fixed at 15 years post-diagnosis assumption	SCHARR Ch.8 results	Time Horizon
1.3.1	Model includes MRI but parameters from PSA-biopsy era	"As mpMRI was not part of the CAP trial protocol, the model similarly assumed that all men with elevated PSA levels underwent biopsy directly."	SCHARR Section 7.2.1, p.81	Clinical Pathway
1.3.2	Systematic overstatement of diagnostic harms due to pre-MRI pathway parameters	"As no data were identified describing variation in mpMRI sensitivity by stage or grade, uniform sensitivity was assumed across all cancers."	SCHARR Section 10.4, p.183	Clinical Pathway
1.3.3	Biopsy complications from transrectal era; transperineal now standard	"Although the CAP trial used TRUS, the current model uses LATP biopsy. To reconcile this difference, biopsy accuracy in the model was adjusted"	SCHARR Section 7.2.1, p.81	Clinical Pathway
1.3.4	MRI sensitivity/specificity data incomplete	"Sensitivity and specificity values for mpMRI and biopsy were based on Ahmed et al. (2017). As no data were identified describing variation in mpMRI sensitivity by stage or grade, uniform sensitivity was assumed"	SCHARR Section 10.4, p.183	Data Gap
1.4.1	Treatment parameters based on pre-active surveillance era data	"more than half of men who initially start on an active surveillance pathway will move onto having radical treatments (surgery or radiotherapy) over 15 years"	Narrative Section 4.7.2, p.15	Data Quality
1.4.2	Treatment harms from older open surgery; robotic surgery outcomes not reflected	"At 6 years after treatment, 36-50% men having radical treatments will have erectile problems, 5-13% will be incontinent of urine"	Narrative Section 4.7.2, p.15	Data Quality
1.4.3	Active surveillance QoL not properly valued; detection treated as immediate harm	"Those who do not receive treatment but are under active surveillance may also feel distressed by the impression that they have an 'untreated' cancer."	Narrative Section 4.4, p.12	Model Structure
1.4.4	No active surveillance progression data (rates, QoL, psychological impacts)	"A limitation to using EQ-5D is that the connection between these 5 domains and the benefits and harms we see in screening is not always obvious or explicit."	Narrative Section 4.7.2, p.15	Data Gap
1.4.5	Treatment pathway assumed identical regardless of stage at diagnosis	"The treatment pathway was modelled to be the same under usual care and in each screening strategy."	Narrative Section 4.4, p.11	Model Structure
1.5.1	Risk stratification bolted on to population model, not foundational design	Model originally designed for population screening; risk stratification added as secondary analysis rather than core architecture	SCHARR methodology	Model Structure
1.5.2	Combined risk factors not modelled (Black + family history, multiple relatives)	"There was inconsistency... because of no data describing three-factors correlations: BRCA carrier, familial risk, and ethnicity"	SCHARR Section 10.3, p.179	Model Structure
1.5.3	Family history definition too broad—captures ~1/3 of men	"Men with a family history of prostate, breast, or ovarian cancer make up about a third of all men."	Coversheet Section 4.4, p.5	Data Quality
1.5.4	No subgroup analyses for Black men (age, ancestry, family history, SES)	"There is a clear need for UK-specific data on the Black population, particularly regarding GGG distribution by age at diagnosis, stage at diagnosis by age"	SCHARR Section 10.4, p.181	Data Gap
1.6.1	Acknowledged: "better fit would make screening less cost-effective"	"The model predicted prostate cancer deaths as a proportion of those diagnosed in the non-screening arm, higher than in the CAP data"	SCHARR Section 7.2.3, p.82	Calibration
1.6.2	Calibration against contaminated baseline (existing opportunistic testing)	"Due to the uncertainty around how much PSA testing of asymptomatic men is happening in current practice, it is difficult to clearly understand what and how much change to PSA testing practice"	Narrative Section 4.3, p.11	Calibration
1.6.3	Model calibration limitations acknowledged	"Calibration results showed that the NHD parameters were split across several distinct regions of parameter space, what impacted probabilistic results."	SCHARR Section 10.3, p.179	Calibration
1.7.1	Circular reasoning: model assumptions generate estimates that justify conclusions	"Overdiagnosis is a model-dependent construct rather than a directly observable outcome."	SCHARR Section 10.2.2, p.178	Logic

#	Issue Description	Exact Quote/Evidence	Reference	Category
1.7.2	Overdiagnosis rates (40-80%) at upper end vs other models	<i>"Estimates of overdiagnosis varied widely (6–82%), both across and within models."</i>	SCHARR Section 10.2.2, p.177	Data Quality
1.7.3	Rates not adjusted for MRI pathway (reduces insignificant cancer detection)	<i>"MRI pathway expected to reduce detection of clinically insignificant cancers but model parameters from pre-MRI era"</i>	SCHARR methodology	Data Quality
1.7.4	Overdiagnosis conflated with overtreatment; AS men not distinguished	<i>"screening in BRCA carriers led to substantial overdiagnosis, ranging from 13% with a single screen at age 45 to 79% at age 72" [includes men on AS]</i>	SCHARR Section 8.4.1, p.138	Framing

PART 2: NSC EVIDENCE REVIEW COVERSHEET

#	Issue Description	Exact Quote / Evidence	Reference	Category
2.1.1	BRCA recommended despite SCHARR stating "no data" for BRCA population	<i>"there are no data on prostate cancer screening, diagnosis, and treatment in the BRCA population"</i>	SCHARR Key Messages p.12	Evidence Standards
2.1.2	81% and 78-79% probability deemed insufficient; no threshold defined	<i>"This strategy was cost-effective at the £20,000/QALY threshold in 81% of runs" [Black men] but deemed uncertain</i>	SCHARR Section 8.2.3, p.115	Evidence Standards
2.1.3	Aggressive cancer rationale applied to BRCA but not Black men (same characteristic)	<i>"men with a BRCA gene variant are more likely to develop faster growing and aggressive cancers at an earlier age" [same modelled for Black men]</i>	Coversheet Section 4.3, p.5	Evidence Standards
2.1.4	Trial evidence demanded for Black men/FH; extrapolation accepted for BRCA	<i>"there is a lack of strong evidence from large trials about the balance of harms and benefits for this group of men" [Black men only]</i>	Coversheet Section 4.2, p.5	Evidence Standards
2.1.5	IMPACT trial (prospective BRCA screening study) not cited	<i>Relevant prospective data from IMPACT study on BRCA carrier screening not discussed in consultation documents</i>	Coversheet omission	Evidence Gap
2.2.1	No equality impact assessment despite disproportionate effect on Black men	<i>No published Equality Impact Assessment accompanying consultation despite differential recommendations by ethnicity</i>	Not published	Process
2.2.2	No BRCA implementation plan; only ~35% know carrier status by age 50	<i>"Importantly, not all men with a BRCA1/2 gene mutation may know they have one... there has been a rapid rise in genetic testing in recent years and the model is therefore likely to underestimate"</i>	Narrative Section 5.3.1, p.18	Process
2.2.3	BRCA testing cost-effectiveness not evaluated	<i>"this study did not look at whether testing for the BRCA gene itself is cost-effective—that would require separate research"</i>	SCHARR Key Messages p.10	Data Gap
2.2.4	No cost-effectiveness threshold stated; allows arbitrary decisions	<i>"There is ongoing debate about what WTP threshold is most appropriate for screening programmes"</i>	Narrative Section 4.9, p.17	Process
2.3.1	Perfect uptake for BRCA (~100% CE); realistic 36% for others (78-81% CE)	<i>"both single and repeat screening scenarios with perfect uptake had a 100% probability of being cost effective for BRCA carriers"</i>	SCHARR Section 8.4.3, p.142	Evidence Standards
2.3.2	36% uptake from CAP (2001-2009); modern programmes achieve 60-70%	<i>"The model assumed the base case... uptake of prostate cancer screening to be 36%, based on data from the UK CAP Trial."</i>	Narrative Section 4.2.2, p.10	Data Quality
2.4.1	States only Lithuania has national screening; multiple countries implementing	<i>"Lithuania appears to be the only country with a national approach to offering PSA-based early detection"</i>	Coversheet Section 2.3, p.3	Factual Error
2.4.2	Overdiagnosis highlighted for Black men (44%) but omitted for BRCA (40-50%)	<i>"about 44% of prostate cancers detected would be overdiagnosed" [Black men] but BRCA overdiagnosis 13-79% not highlighted similarly</i>	Coversheet Section 4.2, p.5	Framing
2.4.3	Mortality benefit for Black men understated; only conservative 4-yearly figure	<i>"over a 15-year period, an additional 571 prostate cancers would be detected and around 7 to 11 deaths prevented"</i>	Coversheet Section 4.2, p.5	Framing
2.4.4	TRANSFORM framing misleading; 5+ years to report while recommending against screening	<i>"The TRANSFORM trial anticipates that it will be able to share data in the next three years."</i>	Coversheet Section 5, p.6	Framing
2.4.5	Per-person mortality reduction larger for Black men (higher baseline) not stated	<i>Black men have 2-3x higher baseline mortality; proportional benefits greater but absolute terms not emphasised</i>	Coversheet omission	Omission
2.4.6	Number needed to screen comparison to other programmes not provided	<i>No comparison of NNS with breast, bowel, cervical screening programmes to contextualise findings</i>	Coversheet omission	Omission
2.4.7	PROFILE study findings not discussed	<i>PROFILE study data on high-risk men not incorporated into consultation analysis</i>	Coversheet omission	Omission

PART 3: EVIDENCE REVIEW NARRATIVE

3.1-3.3: Outdated Data, Statistical Errors, Harm Emphasis

#	Issue Description	Exact Quote / Evidence	Reference	Category
3.1.1	States PCPT "more than ten years old" when actually 1993-2003 (20+ years)	<i>"the amount of PSA in the blood across the population was drawn from data from a US screening trial (the PCPT Trial). Though these data are more than ten years old"</i>	Narrative Section 4.2.1, p.10	Factual Error
3.1.2	CAP 36% uptake used as benchmark; inappropriate for national programme	<i>"The model assumed the base case... uptake of prostate cancer screening to be 36%, based on data from the UK CAP Trial."</i>	Narrative Section 4.2.2, p.10	Data Quality

#	Issue Description	Exact Quote / Evidence	Reference	Category
3.1.3	Cost year 2022/23 but clinical parameters older; not consistently updated	"All costs were reported in pounds sterling for the year 2022/23" but clinical parameters from older sources	Narrative Section 4.8, p.16	Data Quality
3.2.1	78.9% 10-year survival conflates overall with cancer-specific (~90%)	"nearly 8-in-10 people (78.9%) diagnosed with prostate cancer survive for 10 or more years after their diagnosis"	Narrative Section 2.1, p.2	Factual Error
3.2.2	False positive rate: 72% in Sec 4.2.1 vs 61-72% in Sec 3.3—unexplained	"Around three quarters (72%) of people with a raised PSA do not have prostate cancer" vs "61-72% of people with a raised PSA level"	Narrative Sections 3.3, 4.2.1	Inconsistency
3.2.3	Treatment harms: 66% ED at 6mo (Sec 2.2) vs 36-50% at 6yr (Sec 4.7.2)	"66% (two thirds) will experience moderate or severe erectile dysfunction" [6 months] vs "36-50% men having radical treatments will have erectile problems" [6 years]	Narrative Sections 2.2, 4.7.2 p10	Framing
3.2.4	Family history definition captures ~1/3 of men (too broad)	"A family history was taken to mean any first-degree relative with breast, ovarian or prostate cancer... This sub-group included about one-third of all men."	Narrative Section 5.4.1, p.19	Data Quality
3.2.5	AS conversion "more than half" at 15yr vs ProtecT actual 61%	"more than half of men who initially start on an active surveillance pathway will move onto having radical treatments (surgery or radiotherapy) over 15 years"	Narrative Section 4.7.2, p.15	Factual Error
3.3.1	Linguistic asymmetry: benefits "may/could"; harms stated as facts	"Screening can be beneficial" vs "The most common lifelong harms associated with surgery include urinary incontinence"	Narrative Section 2.1-2.2	Framing
3.3.2	Structural ordering: harms (paras 4-7) before benefits (para 3)	Document structure places detailed harm descriptions before benefit discussion in Section 2	Narrative Section 2	Framing
3.3.3	Harms enumerated with percentages; benefits described generally	"71% (nearly three quarters) will find it difficult to control their bladder" vs benefits described without equivalent specificity	Narrative Section 2.2, p.4	Framing
3.3.4	No "what if we don't screen" scenario (metastatic disease, preventable deaths)	Document does not present counterfactual scenario of consequences of not screening high-risk men	Narrative throughout	Omission
3.3.5	Emotive language for harms ("severe pain", "life-long"); neutral for benefits	"severe pain, fractures, or spinal cord compression" described emotively; mortality benefit reduction described neutrally	Narrative Section 2.2, p.3	Framing
3.3.6	"80% would not benefit" ignores AS recipients with minimal side effects	"The majority of men (c.80%) whose prostate cancers are identified through screening would not benefit in terms of preventing prostate cancer deaths"	Narrative Section 2.2, p.4	Framing

3.4.1	No UK-specific data on Black men despite NHS registry availability	"This assumption was informed by US-based data, as no equivalent UK data were identified"	SCHARR Section 10.4, p.181	Data Gap
3.4.2	No GRADE ratings; readers cannot distinguish RCT from expert opinion	Evidence quality ratings (GRADE or similar) not provided for key model inputs	Narrative throughout	Process
3.4.3	No patient preferences data (discrete choice experiments)	Patient preference data for screening trade-offs not incorporated into model	Narrative Section 4.7.2	Data Gap
3.4.4	No international comparison (countries with organised screening)	Limited comparison with outcomes from countries with organised prostate screening programmes	Narrative throughout	Data Gap
3.4.5	BRCA "more conclusive"; Black men "great uncertainty"—not quantified	"The model is more conclusive about the balance of benefits and harms compared to cost of screening men with a known BRCA1/2 gene mutation" vs "great deal of uncertainty" for Black men	Narrative Sections 5.2.2, 5.3.2	Inconsistency
3.4.6	No combined risk factor analysis (Black + FH, BRCA + Black)	"There was inconsistency... because of no data describing three-factors correlations"	SCHARR Section 10.3, p.179	Data Gap
3.4.7	No comparison with other funded NHS interventions (cost/QALY context)	No contextualisation of cost per QALY against other NHS-funded interventions	Narrative Section 4.9	Data Gap
3.4.8	No discussion of current opportunistic testing harms	"Current PSA testing practice is an area of high uncertainty within the model"	Narrative Section 4.3, p.10-11	Omission
3.5.1	Ecological fallacy: population statistics applied to individual decisions	Population-level overdiagnosis rates presented without guidance on individual risk assessment	Narrative throughout	Logic
3.5.2	Circular reasoning: overdiagnosis estimates depend on uncertain assumptions	"Overdiagnosis is a model-dependent construct rather than a directly observable outcome"	SCHARR Section 10.2.2, p.178	Logic
3.5.3	WTP threshold debate acknowledged but £20,000 used without sensitivity	"There is ongoing debate about what WTP threshold is most appropriate for screening programmes"	Narrative Section 4.9, p.17	Logic
3.5.4	Lead time bias acknowledged but not addressed in presentation	Lead time effects acknowledged but results presented without adjustment for comparison	Narrative Section 4.1	Logic
3.5.5	Model designed for "screen all men" applied to "which groups benefit"	Model architecture designed for population screening question applied to risk-stratified question	Narrative throughout	Logic
3.5.6	Same limitations cited against Black men but ignored for BRCA	"There is still too much uncertainty over the benefits and harms" [Black men] but BRCA recommended despite "no data"	Narrative throughout	Logic

PART 4: CRUK/NSC INFOGRAPHIC

#	Issue Description	Exact Quote / Evidence	Reference	Category
4.1.1	Combines incompatible studies: Göteborg-2, CAP, ERSPC, ProtecT	"based on the Göteborg II screening study... deaths prevented in men aged 50-69 from the CAP screening trial... and in men aged 55-69 from the ERSPC screening trial"	Infographic Supporting doc p.1	Data Quality
4.1.2	Temporal mismatch: deaths 15-23yr; overdiagnosis 4yr; harms 12yr	Different follow-up periods combined: Göteborg-2 (4 years), CAP (15 years), ERSPC (23 years), ProtecT (12 years)	Infographic Supporting doc	Data Quality
4.1.3	Modern MRI pathway (fewer harms) but old non-MRI mortality (smaller benefit)	Göteborg-2 MRI pathway used for diagnosis but CAP/ERSPC non-MRI mortality figures	Infographic Supporting doc	Data Quality
4.1.4	Göteborg-2 pathway but CAP/ERSPC mortality—different populations/protocols	Swedish screening pathway applied to UK/European mortality data from different protocols	Infographic Supporting doc	Data Quality
4.1.5	Age ranges differ: 50-60 (Göteborg-2) vs 50-69 (CAP) vs 55-69 (ERSPC)	"in men aged 50-60 (Hugosson et al, NEJM 2024), deaths prevented in men aged 50-69 from the CAP screening trial... and in men aged 55-69 from the ERSPC"	Infographic p.3 footnote	Data Quality
4.2.1	Grade Group 3-4: 12% of 28 = 3.36 (rounds to 3); infographic shows 4	"12% of prostate cancers will be Grade Group 3-4" of 28 diagnosed = 3.36, shown as 4	Infographic calculation	Calculation
4.2.2	"Up to 20 overdiagnosed" based on "clinical expertise"—not data-derived	"The estimates of people overdiagnosed and overtreated are based on a mixture of clinical expertise and the ProtecT trial"	Infographic Supporting doc p.2	Calculation
4.2.3	"12 overtreated" calculation opaque; methodology not shown	Calculation method for 12 overtreated figure not transparently documented	Infographic Supporting doc	Calculation
4.2.4	Overtreatment logic combining AS switching with GG2 treatment unclear	"This number assumes that some men who switch from active surveillance to radiotherapy/surgery within 15 years did so unnecessarily"	Infographic p.3 footnote	Calculation
4.3.1	Visual hierarchy: large text for "20 overdiagnosed"; footnoted "2 lives saved"	"Up to 20 likely overdiagnosed" prominent; "Up to 2 lives will be saved by inviting men to screening**" with double asterisk	Infographic p.3	Framing
4.3.2	Harms as facts; benefits with double-asterisk qualifiers	"**Assumes all invited men accept a PSA test" qualifier applied to benefits only	Infographic p.3 footnote	Framing
4.3.3	"Up to 20" and "Up to 2" create false equivalence; 20 is remembered	Both figures use 'Up to' framing but psychological salience favours larger number	Infographic p.3	Framing
4.3.4	Treatment harms in highlighted box; mortality benefit footnoted	Treatment harms box prominent; mortality benefit in footnote position	Infographic p.3	Framing
4.3.5	Icon representation may misrepresent proportions if not calibrated	28 figures shown diagnosed but scaling to harms/benefits may not be proportional	Infographic p.3	Framing
4.4.1	No "1,000 not screened" comparator; impossible to interpret outcomes	No parallel pathway showing outcomes for 1,000 men NOT offered screening for comparison	Infographic omission	Omission
4.4.2	Cancer progression harms absent (metastases, spinal cord compression, death)	Harms of NOT screening (metastatic disease, suffering, death) not shown for comparison	Infographic omission	Omission
4.4.3	High-risk group context missing; general population figures only	Figures for general population screening only; no high-risk group outcomes shown	Infographic omission	Omission
4.4.4	Active surveillance option not explained for "overdiagnosed" men	Overdiagnosed men portrayed as harmed without explaining AS pathway minimises treatment	Infographic omission	Omission
4.4.5	Modern MRI-first pathway benefits (reduced biopsies) not mentioned	MRI-first pathway reduces unnecessary biopsies but this benefit not shown	Infographic omission	Omission
4.4.6	Quality of life for men on AS vs treatment not distinguished	All diagnosed men grouped together regardless of AS vs treatment pathway	Infographic omission	Omission
4.4.7	No comparison with other screening programmes (breast, bowel, cervical)	No contextualisation against other UK screening programme statistics	Infographic omission	Omission
4.4.8	Sources listed but methodology for key figures not explained	References cited but derivation methodology not transparent for lay readers	Infographic Supporting doc	Process

PART 5: MODEL DESIGN AND INHERITED BIAS

#	Issue Description	Exact Quote / Evidence	Reference	Category
5.1.1	Model commissioned 2010 for "screen all men 50-70"—obsolete question	Original SCHARR model from Chilcott 2010/2013 designed for population screening question	Chilcott 2010 paper	Model Design
5.1.2	Current question ("which high-risk groups benefit") fundamentally different	2025 question about targeted screening differs fundamentally from original population screening question	SCHARR 2025 vs 2010	Model Design
5.1.3	Population screening framing virtually guarantees marginal findings for subgroups	Model architecture designed for average-risk population dilutes findings for high-risk subgroups	SCHARR methodology	Model Design

#	Issue Description	Exact Quote / Evidence	Reference	Category
5.1.4	No serious advocate proposes unstratified PSA screening; model answers wrong question	<i>Contemporary clinical practice uses risk-stratified approaches not modelled as base case</i>	SCHARR methodology	Model Design
5.2.1	Core architecture unchanged 15 years; incremental updates not reconceptualisation	<i>Model structure retained from original development with parameter updates rather than redesign</i>	SCHARR vs Chilcott 2010	Model Design
5.2.2	Treatment utility values from pre-active surveillance era studies	<i>"The amount by which EQ-5D scores were reduced... following a diagnosis of prostate cancer was based on data from the 2024 NHS Cancer Quality of Life Survey"</i>	Narrative Section 4.7.2, p.15	Data Quality
5.2.3	No MRI-era pathway benefits incorporated despite 7+ years standard practice	<i>PROMIS trial 2017 established MRI-first pathway but model parameters from pre-MRI era</i>	SCHARR methodology	Data Quality
5.2.4	Same 3.5% discount rate from 2010 retained despite 15 additional years ERSPC	<i>Discount rate unchanged from original model despite longer follow-up data now available</i>	SCHARR methodology	Model Design
5.2.5	2010 PSA sensitivity assumptions retained without re-evaluation	<i>"In the model, the amount of PSA in the blood across the population was drawn from data from a US screening trial (the PCPT Trial)"</i>	Narrative Section 4.2.1, p.10	Data Quality
5.2.6	Natural history parameters from pre-MRI diagnostic era	<i>Natural history model calibrated to data from before MRI pathway implementation</i>	SCHARR methodology	Data Quality
5.3.1	Structure ensures harms immediate/certain; benefits distant/discounted	<i>"Harms can arise as early as 2 weeks after beginning treatment" vs benefits accruing over 15-23 years</i>	Narrative Section 2.2, p.4	Model Design
5.3.2	Every sensitivity analysis same result—predetermined conclusion	<i>Multiple sensitivity analyses all confirm base case finding suggesting structural determination</i>	SCHARR Ch.8 results	Model Design
5.3.3	Model confirms hypothesis rather than testing it	<i>Sensitivity analyses confirm rather than challenge base case assumptions</i>	SCHARR methodology	Model Design
5.3.4	Deterministic shows greater benefit than probabilistic—unexplained discrepancy	<i>"This contrasts sharply with the probabilistic analysis assuming perfect uptake" - deterministic more favourable</i>	SCHARR Section 8.2.3, p.115	Model Design
5.3.5	Lead time captured but mortality benefit discounted asymmetrically	<i>Lead time bias adjustments applied but asymmetric treatment of benefits vs harms</i>	SCHARR methodology	Model Design
5.3.6	Overdiagnosis accumulated; mortality benefit spread and discounted	<i>Overdiagnosis counted at detection; mortality benefit discounted over projection period</i>	SCHARR methodology	Model Design
5.4.1	Perfect uptake for BRCA (~100% CE); realistic 36% for Black men/FH (78-81%)	<i>BRCA cost-effectiveness with perfect uptake; Black men with realistic 36% CAP uptake</i>	SCHARR p.142 vs p.115	Evidence Standards
5.4.2	Lack of trial evidence cited against Black men but not BRCA	<i>"there is a lack of strong evidence from large trials" for Black men; BRCA has "no data" but recommended</i>	Coversheet pp.4-6	Evidence Standards
5.4.3	NSC worked around limitations for BRCA (aggressive cancer rationale, perfect uptake)	<i>BRCA recommendation uses perfect uptake and aggressive cancer logic not applied to Black men</i>	Coversheet pp.4-5	Evidence Standards
5.4.4	Identifiability: BRCA requires expensive testing (~35% known); Black men self-declare	<i>BRCA identification requires genetic testing; Black ethnicity self-identified at no cost</i>	Coversheet p.4	Evidence Standards
5.4.5	Hardest to identify group approved; easiest to identify rejected	<i>BRCA (requires testing, ~35% known) approved; Black men (self-identify) rejected</i>	Coversheet	Evidence Standards
5.4.6	"Aggressive cancer" logic applied selectively despite same characteristic	<i>"men with a BRCA gene variant are more likely to develop faster growing and aggressive cancers" - same modelled for Black men but different conclusion</i>	Coversheet pp.4-5	Evidence Standards
5.5.1	Time horizon matching natural history (20-25 years or lifetime) - RECOMMENDATION	<i>Model should use time horizon matching prostate cancer natural history not artificial 15-year cutoff</i>	Recommendation	Recommendation
5.5.2	Contemporary MRI-first, transperineal biopsy, robotic surgery as baseline - RECOMMENDATION	<i>Model should use contemporary clinical pathway as base case not historical practice</i>	Recommendation	Recommendation
5.5.3	Risk stratification foundational design, not bolted-on adjustment - RECOMMENDATION	<i>Future model should be designed for risk-stratified screening question from outset</i>	Recommendation	Recommendation
5.5.4	Consistent evidence standards, uptake assumptions across all groups - RECOMMENDATION	<i>Same uptake assumptions and evidence standards should apply to all risk groups</i>	Recommendation	Recommendation

PART 6: PROCESS AND GOVERNANCE

#	Issue Description	Exact Quote / Evidence	Reference	Category
6.1.1	Expert group identities not published	<i>Names and affiliations of expert advisory group members not disclosed with consultation</i>	NSC website	Process
6.1.2	Model code not published for independent verification	<i>SCHARR model code not made available for independent review or replication</i>	SCHARR report	Process
6.1.3	Stakeholder feedback and responses not published	<i>Phase 1 and Phase 2 stakeholder feedback and NSC responses not published</i>	Consultation docs	Process
6.1.4	Decision-making criteria for probability thresholds not disclosed	<i>No stated threshold for probability of cost-effectiveness required for recommendation</i>	Coversheet	Process
6.1.5	Conflicts of interest for advisers not published with consultation	<i>Declaration of interests for expert group members not included in consultation documents</i>	Consultation docs	Process
6.2.1	No equality impact assessment published	<i>No published EIA despite differential recommendations affecting ethnic groups</i>	Not published	Equality
6.2.2	Public Sector Equality Duty compliance unclear	<i>No documentation of how PSED requirements were considered in decision-making</i>	Not addressed	Equality
6.2.3	Black men disproportionately affected; analysis absent	<i>Black men 2-3x higher mortality from prostate cancer but no health inequalities analysis</i>	Coversheet pp.4-6	Equality
6.2.4	Patient and public involvement in modelling choices unclear	<i>"patient and public voice (PPV) members" involved but role in key modelling decisions unclear</i>	SCHARR report	Process
6.2.5	Accessibility of consultation documents for lay readers poor	<i>Technical documents require specialist knowledge to understand; no lay summary provided</i>	All documents	Process
6.3.1	Consultation period over Christmas/New Year period	<i>Consultation opened late November 2025 with deadline February 2026, spanning holiday period</i>	Consultation timing	Process
6.3.2	Technical complexity of documents limits meaningful public engagement	<i>185-page SCHARR report and technical narrative limit public participation</i>	All documents	Process
6.3.3	No plain English summary of key findings and uncertainties	<i>Infographic oversimplifies; no intermediate summary for informed public engagement</i>	Consultation docs	Process
6.3.4	Infographic jointly branded CRUK/NSC may appear more authoritative	<i>Joint branding with major cancer charity may lend undue authority to contested figures</i>	Infographic	Process
6.3.5	Response mechanism unclear for detailed technical submissions	<i>How detailed technical critiques will be addressed in decision-making not specified</i>	Consultation process	Process
6.4.1	Decision announced same week as TRANSFORM trial launch	<i>Announcement timing coincided with TRANSFORM trial launch 21 November 2025</i>	Press coverage	Process
6.4.2	Sir Chris Hoy disclosure timing and policy announcement proximity	<i>High-profile patient announcement proximate to policy decision timing</i>	Press coverage	Process
6.4.3	TRANSFORM designed to answer question already answered negatively	<i>Trial commissioned to address uncertainties after negative recommendation already made</i>	Coversheet p.6	Process
6.4.4	5+ year wait for TRANSFORM while recommending against screening	<i>"The TRANSFORM trial anticipates that it will be able to share data in the next three years"</i>	Coversheet p.6	Process
6.4.5	High-risk men told to wait for evidence already available	<i>81% probability cost-effective for Black men deemed insufficient; told to wait for TRANSFORM</i>	Coversheet pp.4-6	Process
6.4.6	BRCA pathway may remove high-risk men from TRANSFORM eligibility and impact findings	<i>Men identified through BRCA screening may become ineligible for TRANSFORM recruitment</i>	Consultation docs	Process
6.4.7	Private testing surge predictable consequence not addressed	<i>Negative recommendation likely to increase private testing; implications not discussed</i>	Not addressed	Process
6.4.8	NHS "informed choice" pathway contamination of TRANSFORM not modelled	<i>Existing opportunistic PSA testing will contaminate TRANSFORM control arm; not addressed</i>	Not addressed	Process

P202	Affected Comment: Yes it has affected a member of my wife's family. The person concerned was not screened and although other members of his family had had the disease it was not picked up that there were any concerns and he was diagnosed by chance when he attended his GP complaining of night time frequency Evidence Comment: I believe that the committee have missed the important factor about screening those at increased risk such as those with familial links to the disease and those of black origin where the risk is shown to be higher Discussion comment: Please implement a screening programme for those with familial links and black people. Whilst the PSA test in itself will give false positives this can be linked to MRI scanning to determine risk and improve the outcomes for people with the disease. At the very least this needs to be implemented as a large scale national trial and not left for men to have this Disease picked up by chance when there is then an increased risk of a poor outcome Recommendation comment: I think it should be recommended as that would give all those with an increased risk a better chance of long term survival without the debilitating effects of having advanced cancers when they are detected Alternatives comment: I don't think that they can other than by continuing to treat more patients with advanced or late stages of the disease Other comments: Just get screening started

P203	Affected Comment: Relative, in the past. Evidence Comment: The reference to Sweden being 'different' is puzzling, to put it politely. The different population profile of the U.K./England makes screening MORE useful. Discussion comment: The conclusion is tired and suspect. A raised PSA level does not mean invasive further testing, in most cases. Targeted MRIs are hardly invasive. In any case, the conclusion that 'harm' outweighs benefit is suspect. One 'harm' is allegedly that those who are found to require further investigation are maybe needlessly worried. But what about the worry of the whole population that they are not being tested when they could be?! Next, and more centrally, the various 'harms' from screening are surely incommensurate with the harm of death from undiagnosed cancer. Trading off harms by QALYs et al does not work here, even if and when done 'properly'. Finally, what about the government's/ Health Secretary's three overarching priorities (prevention, community services where possible and AI/IT)? Yet when a real opportunity to do prevention arises, the usual suspects decide to live in the past with tired and outdated 'evidence'...and reject a preventative approach! Recommendation comment: Yes it should be. I have explained why in the preceding paragraph! Alternatives comment: N/A Other comments: No

P204	Affected Comment: I had prostate cancer – PSA ***** and secondaries from skull to ankles. I also have ***** friends with PC – Two have died. I am now ***** years cancer free. Evidence Comment: I had no evidence of PC – urine system unaffected and it wasn't till secondaries in the spine generated back problems. that I started asking questions. GP avoided PSA and it was 9 months till I became desperate and went private based on the GP's latest misdiagnosis of 'it must be an ulcer'. The gastroenterologist identified spinal growths on an X-ray and called for a PSA test. Had I had a routine PSA test then it would have been flagged, probably more than a year earlier. Discussion comment: I speak as a victim of the 'no PSA' school of thought. I was misdiagnosed with a back problem by a rigidly 'no PSA' doctor. He came up with a range of alternatives each of which took months to test out. When finally diagnosed I had a PSA of ***** with secondaries (the cause of the back problem) from skull to ankles including heart and lungs. Happily as part of the Stampede trial I had Prostate and abiraterone which cleared the secondaries in ***** months and the PSA to zero in ***** months, with no surgery or radiotherapy. Without the PSA (proposed by a consultant gastroenterologist) I would have been dead in months rather than alive after 12 years. The 'ostrich approach' proposed for PSA screening seems to miss the point. All involved, Doctor and patient need to know that there is something possibly amiss. I have had several friends diagnosed with Prostate cancer – two of whom were killed by it. All started from a PSA. The threat of overtreatment is in the control of the medical profession. Ignorance of a possible problem is of no benefit to anyone involved. A BRACA diagnosis is an expensive bi-product of a blood test and of no help unless the blood test is required in some way. Recommendation comment: It should be recommended. So please overrule the proposed – no PSA screening – approach proposed. All men deserve the chance to know what is happening to their bodies.

	It is not an insurmountable problem to educate Doctors and patients alike that taking no action for a doubtful PSA reading is a positive reaction. Alternatives comment: PSA test needs to be the root of further investigation, not action. Education is needed that intermediate PSA levels should lead to further monitoring – not necessarily action. Other comments: Explain that prostate cancer can be symptomless, as in my case until the secondaries create damage. Routine tests are the only way to manage this.
P205	Affected Comment: No, but I am aware it affects so many people and is so easily preventable/ reducible! Discussion comment: We need to invest in prevention. We cannot let the treasury determine that savings must be made now so people's lives can wait and increased costs are incurred further down the line. Recommendation comment: It should. It saves lives and it saves money – it is a complete no brainer. Alternatives comment: Do the screening programme! Other comments: Do the screening programme!

P206	Affected Comment: My Father suffered from prostate cancer, which would confirm that I am in a higher-risk category. Evidence Comment: Looking at other European countries and their data was read with the focus on skewing it towards their clear preconceived bias. Discussion comment: 'Short-termism' results in the billions being spent by the NHS getting wasted. Maybe look for a slightly more diverse panel to look at the evidence – although in reality it reads as if the decision was made BEFORE the evidence was gathered. Recommendation comment: It clearly should be recommended. The spend would be cost-neutral once the price of scans and treatment are factored into the equation. Other comments: Screening clearly saves lives.

P207	Affected Comment: Yes. I am coming up to ***** years since receiving a diagnosis of PC. Following 2 slightly elevated routine PSA tests and digital exam my GP referred me into the cancer pathway. MRI revealed ***** significant lesions, one close to the capsule. A subsequent biopsy identified only ***** core with active cells (Gleason 3+3). Concern about inconsistency between the radiology and pathological findings and possible under sampling resulted in a CT/PSA-PET, and repeat biopsy under general anaesthetic. Neither showed any evidence of malignancy. Despite the later results I am now living with a diagnosis of PC, and receiving active surveillance. My recent PSA levels have been ***** and my follow up MRI showed only one small lesion. I cannot fault the thoroughness of the assessment. My subsequent care through GP and Urology has also been excellent. I am comfortable with the active surveillance process. For me and my family the outcome to date has turned out well. However, reaching that point took several, stressful months, and chronic prostatitis following the two biopsies. Given my eventual equivocal and inconsistent results it seems that I was over diagnosed on the basis of the initial MRI, rather than the PSA. I do not regret having received the tests, but they came at some costs. I am fortunate that the stress and anxiety has receded. However, I am aware that other men and their families may have more of a problem carrying a cancer diagnosis, or have opted for radical treatment as a precautionary measure. Evidence Comment: As a retired ***** I am familiar with the evidence reviews and modelling processes work. I found the report thorough and fully support the recommendations. The current evidence gaps are well Rti ulated Discussion comment: I believe strongly that the recommendations should be implemented and only change as and when evidence gaps are filled. I also feel strongly that pressure groups have a role in raising the profile of such issues to drive research, but NOT to attempt to circumvent expert assessment and guidance. Public polls, divorced from the complexities and nuances, should have no influence on scientific or policy decisions. Recommendation comment: Not yet. There are too many sources of harm the the process of diagnosis and treatment. I requested my PSA tests and do not regret doing so. However. The process has come at some cost to me and my family. Alternatives comment: Better evidence based information about PC, it's assessment and treatment. In particular, a careful discussion of the costs and benefits of testing, whether part of a screening programme or not. Other comments:

P208	Affected Comment: I had a PSA test carried out ***** years ago at the request of my doctor's surgery. I had no symptoms at all. I didn't even know what a PSA test was for and didn't even know what the prostate did. My reading was ***** and they offered to monitor me or refer me to urology. I had an MRI and then saw a consultant who offered to take a biopsy. Little did I know what I had let myself into, it was an experience I'm glad I had, as all ***** samples taken were positive with cancer. I opted for my prostate to be removed. I was so glad that I took the opportunity to have the PSA test, as it has saved my life. My PSA levels have remained less than ***** being undetectable. I asked all my male friends and family to take a PSA test and so far five have proved positive and three have opted for a prostate removal. I find it incredible that the PSA is not offered to every male over the age of 40 years under a national screening offer. Thank god for the NHS. Evidence Comment: I have no words, as they are mainly expletives. Discussion comment: None. Recommendation comment: Yes, yes, yes. It saved my life. If I was not offered a PSA test by my doctor's surgery out of the blue, I would have carried on with my life unaware of this cancer growing with in me. Alternatives comment: Please just have a screening service similar to the screening offered to women. Other comments: No.

P209	Affected Comment: Both my father and father-in-law had prostate cancer and both needed active treatment, they both died within 10 years of diagnosis possibly with secondary affects from cancer. I am ***** year old and aware to monitor symptoms but hard to tell if something is prostate related, with the curent news about Chris Hoy and others being given stage 4 diagnosis for a disease that could have been treated earlier if detected I ask the question what can we do to prevent these early unneccesary deaths ? thank you for your consideration Evidence Comment: I am not qualified to answer this question Discussion comment: please introduce a screening programme Recommendation comment: yes definately to be screened Alternatives comment: no i think screening is the most effective way to pick up non symptomatic patients, just like cervical cancer screening Other comments: no
P210	Affected Comment: My father died of prostate cancer, within a short period of time! I am very nervouse fpr myself. Discussion comment: If a PSA test is not reliable then should we not be looking for a better way of testing? It seems to me that if a PSA indicates a problem Wrongly or rightly, surely the follow up would filter out errors in diagnosys? Recommendation comment: Rcomended, for the reasons stated previously. Other comments: Prevention is better than cure! I still think screening would be a step forward with common sence checks a d balances.

Affected Comment:

I have been affected by Prostate Cancer, Diagnosed in ***** at age *****. Radical prostatectomy performed *****. My father died of secondary cancers brought about by Prostate Cancer after having his Prostate removed in *****. Since my diagnosis I have been very open about my condition and am amazed just how many men are affected by it. Also amazed at just how many men have kept quiet through embarrassment on being affected by this condition. So many that I know personally who never spoke about it until I was quite open about my diagnosis and treatment.

Evidence Comment:

Yes its amazing that I see nowhere that its mentioned how so many men, too many men are being diagnosed far too late because there is no screening programme and how many men are being diagnosed by chance having had absolutely NO symptoms of any kind.

Discussion comment:

Yes I think it is fundamentally flawed. It is now the cause of the highest death rate in the UK having surpassed breast cancer, which has a screening programme. How can this be?

Recommendation comment:

Yes there should definitely be a screening programme. Too many men dying of a cancer that on the whole can be treated.

Also too many men finding out by chance they have Prostate Cancer, as I did my self. I had absolutely no symptoms, was in hospital with a perforated bowel having bloods taken twice a day luckily the doctors tick PSA test on the blood form, which showed a high level and needed further investigation. Further blood tests, an MRI scan followed by a biopsy resulted in a Cancer diagnosis. Followed by surgery as Luckily my cancer was caught early and all confined to the Prostate. I am a Prostate Cancer survivor due to a PSA test and the resulting follow up.

My family has a history of Prostate Cancer and Breast Cancer (my grandmother and sister died of it). Until I read the draft recommendation I had never heard of BRCA 1&2. I've never been screened for it. But now I am worried for my children and grandchildren.

How are people going to find out they have the BRCA gens? Screening?

Alternatives comment:

Could! Could! So what are the alternatives, I don't see them mentioned anywhere.

Other comments:

Yes. Start a screening programme now, start with a PSA test and as things develop, develop the screening programme to suit. Save lives not £££'s.

P212	Affected Comment: Yes, at the age of ***** I asked my GP for A PSA test for no other reason than I want to check whether there was any sign of a raised PSA, My GP fortunately agreed to this after explaining all of the possible ramifications. My initial reading was ***** which rose over ***** months to *****. I was then recommended to have a biopsy which discovered cancer in one side of the prostate. I was then offered differed forms of treatment and chose a prostatectomy. ***** years on I am completely clear of the disease and rely on a PSA test annually to maintain my confidence. Evidence Comment: I have little to comment other than I have considerable concern about relaxing any opportunities to establish whether they might be a presence of the disease and my experience proves that even without family history or existence of the concerning gene or history of prostate problems there is a need for every man to be offered the opportunity to be checked. Discussion comment: I would suggest that both of the above more than cover my thoughts on the review. I fail to see why when every other cancer including breast cancer which is linked to the same gene, have a National screening programme and Prostate Cancer is being denied this despite the increasing number of death every year. Recommendation comment: Most of my arguments for a National Screening programme are covered above and I understand that Prostate Cancer UK amongst others dealing with the disease are deeply disappointed at the review statements. Alternatives comment: Perhaps more money could be directed to research of the disease and more comprehensive and intensive methods of screening. Other comments: None

P213	Affected Comment: I had a prostate cancer 'scare' 12 months ago when I was being treated for another condition. Fortunately it turned out to be a false alarm but at the time it was very concerning. I have 2 friends who have both had it and both are still alive due to early intervention. Evidence Comment: No comment. Discussion comment: There is clearly an unmet need here. Given the large numbers of men affected a screening g program has the potential to save a significant number of lives and improve outcomes for others. There may be limitations initially and the program may not be perfect to start with, but programs and effectiveness can be improved over time, but you have to start somewhere. Recommendation comment: Yes screening should be in place. Start with a targeted program and widen out as accuracy improves. Alternatives comment: More publicity and more research can only help. However as knowledge improves it will only increase the demand for screening as the population realises that outcomes can be improved by early intervention. Other comments: You have to start somewhere – get on with it. Doing nothing is a failure.

P214	Affected Comment: Yes. My husband was diagnosed with prostate cancer ***** years ago. Without testing his condition would still be undiagnosed. Evidence Comment: Yes. Most of the evidence is based on statistics. The human factor is sadly missing. Discussion comment: Yes. Forget statistics: focus on real people. Recommendation comment: It should be recommended. It will diagnose people without any obvious symptoms. Alternatives comment: The proposed screening is a simple blood test. That's good enough. Other comments: No.
P215	Affected Comment: My father died of prostate cancer and was never properly diagnosed. I too had PC but had to insist that my GP tested me. After various tests I received radiotherapy and now in remission. Recommendation comment: If offered as a routine, it would surely save many deaths. The negatives of screening are a smokescreen for cost savings. No convincing cost benefit analysis proves the case against screening Alternatives comment: Prevention is always better than cure. Initial PSA tests could be replaced by a simple self test of urine flow.

P216	Evidence Comment: A close friend of mine had no symptoms and only took PSA test as someone recommended it. Turns out he had Stage 3 Prostate Cancer and needed to have it removed. He now suffers from erectile and incontinence problems however if left undetected he would have now faced a terrible prognosis. My own ***** died from prostate Cancer and my ***** have it yet under the new criteria people like me would not even get screened! There should be a full Prostate screening programme for men in similar ways that women have breast and cervical screening, it seems discriminatory without this! Discussion comment: There should be a full Prostate screening programme for men in similar ways that women have breast and cervical screening, it seems discriminatory without this! Recommendation comment: close friend of mine had no symptoms and only took PSA test as someone recommended it. Turns out he had Stage 3 Prostate Cancer and needed to have it removed. He now suffers from erectile and incontinence problems however if left undetected he would have now faced a terrible prognosis. My own ***** died from prostate Cancer and ***** have it yet under the new criteria people like me would not even get screened! There should be a full Prostate screening programme for men in similar ways that women have breast and cervical screening, it seems discriminatory without this! Alternatives comment: Alternatives to screening have not been well communicated, I'm not aware of them!
P217	Affected Comment: My husband has this condition, fortunately picked up by a PSA test when he went for a private well man check up before he retired. He is now monitored well by the nhs, but we think he had had it for years and screening would have picked it up earlier, then the ops and worry would have been avoided. Recommendation comment: Should be recommended to save operations, tests and worry.

	Alternatives comment: There are support groups around, but just more publicly, encouragement and support would help.
P218	Affected Comment: My dad died early of PC – undiagnosed until too late, so I have been having my PSA checked 6 monthly for several years. My result in ***** was ***** (under the NICE guidelines for further investigation for a ***** year old). It was only because I could show that it had increased from ***** to ***** in 6 months that I was “allowed” to progress to MRI and biopsy. Cancer detected ***** in ***** cores. Had HIFU in ***** and will continue to be monitored closely for the rest of my life!! Early detection is absolutely critical to keeping all of your options open. The current decision is being based solely on removal and RT as options – which can a just not true. If you consider the focal therapies it is very worthwhile detecting early and treating Evidence Comment: As above – not including focal therapies Discussion comment: It's murderous Recommendation comment: It should – reasons above Alternatives comment: Not appropriate a screen all men

P219	Affected Comment: 2 close family 4 close friends. Evidence Comment: Not qualified to assess Discussion comment: This affects ethnic people more than white. Why no black men on review? Recommendation comment: Yes. AND – must be followed by MRI; biopsy a few, leave majority alone. Simple screening is not enough. Alternatives comment: Emphasise the family connection – an uncle, a cousin, not just a parent/grandparent. Big, regular campaigns on this

P220	Affected Comment: My brother was diagnosed with high-grade, aggressive prostate cancer at just ***** years old. We lost our mother to cancer when she was *****. To face the possibility of losing my brother in his ***** was terrifying. Crucially, my brother is BRCA Negative. Under your proposed guidelines, he would not be eligible for screening. He would have been told he wasn't "high risk" enough. Yet, he had ***** cancer spreading into his seminal vesicles. If he had relied on your proposed guidelines, he would be terminally ill right now. Instead, he has survived, but only after enduring brutal treatments including surgery and radiation that have permanently affected his health. Evidence Comment: The review fails to account for men with aggressive "sporadic" cancer. You are focusing entirely on genetic flags (BRCA). But my brother has no genetic flag. The evidence you are using creates a blind spot that will kill men like him. You are also dismissing the high risk to Black men as "uncertain," which feels like a failure of duty to a vulnerable group. Discussion comment: I find the conclusion unacceptable. The committee argues that the harms of screening (anxiety/biopsies) outweigh the benefits. Ask my brother about the "harms" of not screening. The harm is finding cancer when it is nearly incurable. The harm is fractures from hormone therapy and bowel failure from radiation. These are the result of catching aggressive cancer too late. Screening prevents that harm. Recommendation comment: Screening must be recommended. We have MRI technology now that prevents unnecessary biopsies. Using 20-year-old arguments about "overdiagnosis" to block a modern screening program is negligent. My brother is alive today because he was tested. Every man deserves that chance, not just the ones with a rare gene mutation. Alternatives comment: We need a culture shift. Men in their 40s are invisible to the NHS regarding prostate cancer. If you won't screen everyone, you must lower the age for PSA discussions to 45 and actively invite men to discuss it, rather than waiting for them to show symptoms. By the time symptoms appear, it is often too late.
P221	Affected Comment: This has directly affected my family. My dad was diagnosed with Prostate Cancer at the age ***** and died ***** years later in *****. If there was a national screening I would have hoped he'd still be here to have met his grandchildren. My father in law was also diagnosed with this after his doctor told him to go for a screening, as well as my uncle. Recommendation comment:

	Should be recommended because cancer can strike any age
P222	Discussion comment: Yes, preventative screening surely outweighs the burden of cost associated with treating late stage prostate cancer. Recommendation comment: Yes, screening is a preventative measure that should be targeted to individuals on a risk-based approach. Literature points to the fact that a person dies of prostate cancer every 45 minutes. A healthcare system, for the people, should be aligned with preventative diagnosis, especially so if the early detection can eliminate death.
P223	Affected Comment: I have an enlarged gland..was under annual checks suddenly hit ***** yo no longer called for the checks.. Condition still developing but no NHS interest..cost cutting at its best. told friends to go for check ups in mid ***** both had cancer and glands removed... no inclination they had prostate cancer.. National checking required to save lives.. Evidence Comment: told friends to go for check ups in mid ***** both had cancer and glands removed... no inclination they had prostate cancer.. Discussion comment: Review and testing saves lives and NHS cost in the long term. Recommendation comment: Definitely screen Alternatives comment: Work and put money into a more accurate screening method.

P224	Affected Comment: I have had 2 friends with prostate cancer, diagnosed through a routine blood test. Both have had prostatectomies as the cancer was caught at a fairly late stage. This procedure has affected their lives forever though they are glad to be alive. A screening programme may well have caught the disease at a much earlier stage. I fully support a screening programme. Evidence Comment: I'm not that well informed to comment Discussion comment: I disagree with the conclusion and recommendation not to screen Recommendation comment: I fully support a screening programme for all men. Prevention is by far better than cure even if it picks up some false positives. Alternatives comment: I don't know. Other comments: I fully support a screening programme.
P225	Affected Comment: I was diagnosed with prostate cancer in ***** at the age of *****. Recommendation comment: Screening is essential to save lives.In my case I had no symptoms but during an investigation of another problem,it was discovered that the gland was enlarged and I was then sent for a PSA test which confirmed the disease.Thankfully it was caught early enough for treatment to be successful. Alternatives comment: N/A

P226	Affected Comment: Yes, I am Stage 4, ***** months down the line. Discussion comment: The same conclusion and warnings could be made about cervical cancer screening, but this is done. Recommendation comment: Automatic screening must be done when a family member has had the disease. An elder brother didn't tell me, he was diagnosed in ***** and died in *****. In ***** I received my own diagnosis. Had I known earlier I could have been tested, and been treated before I reached ***** If you don't want to screen all men that is one think, but at least screen those at elevated risk. Alternatives comment: Men are put off having a DRE and won't visit the doctor until it's too late. Removing the human factor, by developing an ultrasonic rectal probe, might prove more encouraging, to image an enlarged prostate and then follow up with a PSA, and MRI & biopsies if both these things are flagged. There is a national screening once over 50 for bowel cancer, a scope. I myself had this done 5 years ago. If this probe also had an ultrasonic feature, to image the prostate through the rectal wall, the recordings could be studied by urologists, not just gastroenterologists. Every man found to have an enlarged prostate, even if this is benign, should then have a PSA test.

P227	Affected Comment: My father died with it. My brother-in-law is dying with it now. Evidence Comment: I don't think they paid enough attention to the cost of treatment further down the line or the personal cost to the men and their families of dying from something which might have been spotted and treated earlier. Discussion comment: I agree with Roy Lilley that "If Sweden can justify targeted screening with a lower-risk population, how can England justify refusing it in a higher-risk one?" Recommendation comment: It should be recommended but targeted on men at higher risk. It should include MRI imaging rather than biopsy as a second step. Alternatives comment: Support the Assisted Dying Bill. Other comments: No.
P228	Discussion comment: I think it is possible to set up a prostate screening programme if enough planning and effort went into setting up so that over-diagnosis and other concerns are minimised. As a minimum, at least allow men over a certain age to "have a right" (sort of right) to ask for PSA test at least every 2 years, if there is not be a national screening programme. At least allow men to ask their GP for a PSA test and get it. Recommendation comment: I think it should be done. And robust processes in place to deal with false positives and over diagnosis. Following positive PSA, use MRI to confirm. Or at least check it out with biopsy where MRI or a scan indicates it might be needed. And if an aggressive cancer is not present, then monitor it as you might with other slow growing or benign cancers.

P229	Affected Comment: My stage 4 prostate cancer diagnosis came as a complete shock and has had a devastating effect on me and my family. Because there is no screening programme I had to push my GP to agree to a simple (£12) blood test to get my PSA checked. My cancer is incurable so I have had palliative radiotherapy and am on Decapeptyl and Enzalutamide for life or as long as they keep working – this is costing thousands of pounds each month. These medications have severe side effects including muscle wastage and mental impairment, so I can no longer function as well as before diagnosis. An earlier diagnosis would have meant that alternative treatments such as surgery could have been deployed and I would not now be living with a terminal cancer diagnosis, as well as debilitating side effects from the only treatments available to keep the cancer at bay. Evidence Comment: There is no history of either breast or prostate cancer in my family, and so there is no information relating to BRCA genes. Therefore, the NSC was completely wrong to only decide that a tiny fraction of men who know that they have a family history of faulty BRC genes will be offered screening. I think this amounts to discrimination against those men who simply do not have this family history – and this is the majority of those who get prostate cancer. A key question that I have not seen answered is how many men are tested annually for BRCA, and of those how many actually have or go on to develop prostate cancer. The data I have seen is that 1 in 8 men will get prostate cancer, but only 1 in 300 men have a faulty BRCA gene. So the BRCA gene is NOT the main driver of the cause of prostate cancer. Thus, the NSC's approach as to who is eligible for prostate screening is flawed. Discussion comment: How many of the NSC panel were Expert Patients? i.e. lay people who have been diagnosed with prostate cancer. The NSC's recommendations are not wholly valid unless real patients are involved in the discussions. Every fellow prostate cancer patient that I am aware of is appalled by the NSC's decision. Recommendation comment: Screening should be recommended for all men aged 40+. In my own case, screening would have shown up my prostate tumour long before it started to grow outside of the prostate, with metastases in my bones.

	I had no symptoms of prostate cancer whatsoever and I am not in any sort of high risk group. But I still got prostate cancer which is now incurable. Screening would have caught my cancer at an earlier and curable stage. You need to examine the screening process itself and ask what are the probable benefits rather than seemingly only reiterate the possible side effects. The PSA test is painless. A DRE is no more than a slight embarrassment. MRI and CT scans are not unpleasant. A transperineal biopsy is mildly uncomfortable for a few minutes. I know all this because I have actually had them all – unlike, I suspect, anyone on the NSC panel. It would be rather ironic if anyone on the NSC panel were to develop prostate cancer that was only detected at a very late stage. They would then have been a victim of their own decision to not recommend screening for all men, including themselves. Alternatives comment: This is a stupid proposition and question that shows no understanding of what a prostate cancer patient goes through. At present many men only find out they have prostate cancer when it is too late to do anything but provide palliative treatment, often at high cost. How could this situation be improved without a screening programme? When a patient is diagnosed with prostate cancer, the NHS are really good, but they can only treat those patients who are identified – currently through ad hoc blood tests. The government could make things much easier for prostate cancer patients by making this condition an automatic qualifier for Personal Independent Payments because this illness makes earning money to support oneself and one's family so much harder. Other comments: Wes Streeting has publicly stated that he will review the NSC's recommendations and the public's responses in 2026. This needs to happen. Mr Streeting should do the right thing and overrule the NSC and ensure that a national prostate cancer screening programme is made available to all men aged 40+ by the end of 2026.

P230	Affected Comment: No i have annual PSA checks done through the ***** Charity Evidence Comment: Yes if you look at modern risk-based approaches... don't biopsy everyone with a raised PSA... they're MRI'd, risk-stratified and the majority left alone. Sweden, Norway, parts of Germany are doing this. Their data shows what ours would show... target-screen fewer men 'unnecessarily', catch more cancers, treat fewer late-stage cases. Discussion comment: The very groups that make England different are the groups at higher risk... black men who have roughly double the incidence and double the mortality. If Sweden can justify targeted screening with a lower-risk population, how can England justify refusing it in a higher-risk one? Recommendation comment: Yes -a targeted screening programme mirroring the risk-stratified approach used in Sweden, might cost ~£225 million annually. It's a lot but..... cut late-stage presentations by even 20% (and the evidence is, it would be exceed that) the savings in avoided late-stage treatment and end-of-life care are also, a lot. Add to that the value of the life that has been lost in the time it takes you to get going in the morning... the moral picture is unequivocal. Alternatives comment: Science increasingly favours risk-based screening. Everything we need; PSA, MRI, risk-stratification algorithms... all exist. This decision needs over turning – the government claim to want to drive prevention agenda and this is a key part of it Other comments: yes screen for PSA

P231	Affected Comment: This condition affected my husband. Evidence Comment: What is the percentage of men with prostate cancer who have the BRCA gene. How do we know if targeting patients with this gene will be effective if it isn't known what percentage of patients currently with prostate cancer or in the past actually carry it. Discussion comment: Are all patients with symptoms going to be tested for the gene rather than have the PSA test? Recommendation comment: Screening for the BRCA gene should be recommended for my husband It was found early due to me working for the NHS and being aware of the early symptoms but initially he put it down to ageing. It was not known whether he had the BRCA gene. Alternatives comment: Raise awareness of the early symptoms.
P232	Affected Comment: This condition affected my father and 2 friends. None of whom would have known they had it unless they had asked to be checked/ or taken part in trials. I was told by health professionals that many people die with prostate cancer but not of it, hence the lack of priority. This is unacceptable. Regular testing would save lives and resources later along the line in dealing with nursing this condition. Please reconsider your decision. Recommendation comment: Please see above

P233	Affected Comment: My brother ***** was recently diagnosed with late stage Prostate cancer. No known family history or any symptoms until the appearance of blood in urine. Resultant PSA test result in ***** figures! Negative result would have been *****. He's now in long term treatment which will cost the NHS a significant, and continuing, cost. Not to mention his worry and concern and potentially shortened life. Had there been a screening programme available he would have participated. Evidence Comment: The decision is at odds with that of Sweden, Norway and parts of Germany where research has led to Targeted Screening. Which should be introduced in the NHS in England; and Scotland, Waled and N Ireland subject to approval by their Parliaments. Discussion comment: See above Recommendation comment: Screening should be recommended based on evidence from reviews in Sweden & Norway which has resulted in introduction of targeted screening in those countries. England's population has an higher proportion of Black males which means an higher proportion and level of risk of Prostate cancer in the male population Alternatives comment: There are no effective alternatives to a targeted screening programme. Without one it leads to late presentation & diagnosis with resultant continuing higher treatment costs putting more pressure on the NHS budget. Other comments: Reverse the present decision. Invest in improved/alternative tests to the PSA test. I understand there are several alternatives in development and investment should be increased in the research already in progress.

P234	Affected Comment: My husband died of prostate cancer ***** years ago. Had there been screening he may have lived. Symptoms came too late for successful treatment. Our sons are now at risk and their sons too! Screening is so very important Evidence Comment: Having screening for a small group who may never be recognised as requiring screening is farcical and not seeing the real picture Discussion comment: It is useless and just wasting time Recommendation comment: Yes it should for ALL men over 50 and over 40 for those with prostate cancer in the family Alternatives comment: Look for symptoms and be aware of risk by publicity Other comments: Too much time and money wasted on all the wrong things
P235	Affected Comment: My father in law died as a consequence of prostate cancer and late diagnosis. The condition was inoperable and only palliative care was offered. He had previously been fit and well, leading an independent life in his 80s. My husband is therefore at increased risk of developing prostate cancer but with no national screening programme to provide early detection. Discussion comment: The decision not to provide national screening should be reconsidered. The UK is not in line with other countries who provide screening, with evidence to show the benefit of diagnosing earlier. I suspect the decision has been primarily based on availability of finance, but this goes against the NHS 10 year plan, with a shift from treatment to prevention. Recommendation comment: Screening should be recommended to enable earlier diagnosis. One man dies every 45 minutes due to the consequences of prostate cancer. This is shameful : the UK should look to emulate the screening programmes available in Europe and the US. The NHS 10 Year Plan clearly articulates the move from Treatment to Prevention. The same ethos should be applied to screening for prostate cancer.

	Alternatives comment: Provision of screening will help prevent a postcode lottery in terms of diagnosis and treatment. Other comments: Please reconsider. Not providing screening is a flawed judgement and will prevent thousands of men from receiving early diagnosis and curative treatment.
P236	Affected Comment: Yes my father went through a biopsy which made him very ill An MRI would have been a much better option It's a cost effective approach to save on costly chemo drug therapy and end of life care Diagnosis early has to be the gold standard please listen to to the Drs who know. Evidence Comment: I don't know Discussion comment: Needs re looking at and reviewing and costing Recommendation comment: Absolutely recommended to save lives Alternatives comment: Keep it simple and scan to save lives Other comments:

	Listen to the Drs
P237	Affected Comment: I have been diagnosed with Benign Prostate Hypoplasia (BPH). I am currently being treated with Tamsulosin and Finasteride (and experiencing side effects including erectile dysfunction). My mother died of breast cancer at the age of ***** so I understand I am in a higher risk group. I have two friends who are only alive now because of prostate surgery. Recommendation comment: I would personally like to see the development of a more accurate test than PSA or PSA + MRI at which point, a national screening programme should be introduced. Alternatives comment: As above Other comments: As my mother died of breast cancer at the age of ***** and I understand I am in a higher risk group, I would have liked to see men in higher risk groups allowed to volunteer to join the study.

P238	Affected Comment: Yes, I have been diagnosed with Prostate cancer and after initial active surveillance I had hormone and radiotherapy treatment. Evidence Comment: no comment Discussion comment: seems eminently reasonable Recommendation comment: Should not. 1) Current tests are inconclusive and increasingly invasive 2) Predictions of the future onset of aggressive cancer are notoriously imprecise; exacerbated by the general older age of diagnosed men 3) There is a tendency for medical professionals to emphasise the curative benefits of treatment (because we can) as against the likelihood of a cancer's progression or of experiencing side effects 4) Avoids wasting scarce resources Alternatives comment: Education / advertising to emphasise what symptoms / profile (eg race, family history)/ genetic mutations etc should be heeded. In my case an ultrasound on a different organ identified an enlarged Prostate leading to the necessary range of tests required to confirm a cancer diagnosis. Other comments: wider training /advocacy for the involvement of the medical profession in discussing quality v quantity of life with elder patients.
P239	Discussion comment: Men are most likely not to visit GP for any health concerns even if they do appear. Recommendation comment: Screening should be recommended as it is accepted that symptoms are not always obvious and by the time cancer is detected/diagnosed, it is too late for effective treatment.

P240	Affected Comment: My father was diagnosed with Prostate Cancer by chance whilst having an MRI for other unrelated health issues – as the cancer was caught early he was monitored and treated (hormone therapy) as required, and lived to a good age – ***** years My children's father (who is black) went to the GP concerned with pain in his hip, (he had no other symptoms) he was referred to a physio who asked further questions and suspected prostate cancer and referred for further investigation – prostate cancer was confirmed and had already spread to his bones in the pelvic area – he died within a year of being diagnosed at the age of ***** years leaving ***** children without their father Evidence Comment: If it is correct that there was no representation of black men on the panel that made the decision then that is a huge injustice – evidence clearly demonstrates that this group are even more at risk than the white male population (who are also at risk) Serious questions need to be asked as to why there was such an in balance of a diverse representation in a matter that affects the black population so significantly Discussion comment: The conclusion not to provide men with a screening opportunity is fundamentally wrong Recommendation comment: I absolutely think that screening should be offered to men and especially those at high risk due to ethnicity or family history – I have a son who has experienced both his grandfather and father battling prostate cancer with his father losing his life at the age of ***** years a year after diagnosis Early diagnosis provides more men with earlier and less complex treatment options and a chance of survival – in turn less complex treatment and end of life care is more cost effective for the NHS Alternatives comment: I think we should stop talking and instigate a screening programme that will start saving lives and improve the quality of life for men that are able to access earlier less complex treatment plans Other comments: I very rarely respond to consultations but having experienced the impact of undiagnosed until late stage prostate cancer on my children with losing their father and to see my son worry with both his father and grandfather having the diagnosis and being from black heritage I implore you to reconsider the decision not to provide screening for men

P241	Affected Comment: As an over 65 male I believe this decision should be reviewed and should examine closely the evidence from Scandinavia. If a committee of 11 people 8 of whom were men refused to recommend a screening process for a cancer that killed mainly women there would be a national outcry. To the best of my knowledge no blood relatives have been affected by prostate cancer but a friend in his early 60's was diagnosed and although he survived the treatment was invasive and left him with serious side effects.
P242	Affected Comment: My father in law has treatable but incurable prostate cancer making my husband a higher risk Evidence Comment: The panel was not representative. It did not fully consider good practice abroad. It did not consider the full potential diagnostic pathway or the fact that many could be MRI'ed rather than biopsies. Discussion comment: As per above. If a panel about a female cancer contained a majority of males it would be challenged. Other countries screen. Black men and those with familial history have a much greater risk and yet screening of these groups was not considered. Recommendation comment: Yes it should- at the very least for those in a higher risk group. We have all sorts of screening for 'female' cancers. We even do expensive but necessary preventative mastectomies. In the 10 year plan it says one of the three shifts is from treatment to prevention- how does this not meet that clearly stated priority? Alternatives comment: Awareness raising but this has limited value given that many prostate cancers remain undetected until late stages. Other comments: Screen this from black communities and those with familial history

P243	Affected Comment: My partner's (male *****) Father is currently end of life with prostate cancer. His uncle (Father's brother) also had prostate cancer but was successfully treated. My partner therefore has high risk of development but is not invited to routine screening. Instead he has to ask for it (and routinely does) but this doesn't seem right. Evidence Comment: Modern risk-based approaches don't biopsy everyone with a raised PSA... they're MRI'd, risk-stratified (e.g. using family history), and the majority left alone. Sweden, Norway, parts of Germany are doing this. Their data shows what ours would show... target-screen fewer men 'unnecessarily', catch more cancers, treat fewer late-stage cases. Discussion comment: I believe more men should be routinely invited for screening based on risk. Recommendation comment: I believe more men should be routinely invited for screening based on risk. Target-screen fewer men 'unnecessarily', catch more cancers, treat fewer late-stage cases. Alternatives comment: Continued awareness raising of common symptoms. This however should not replace risk based screening. Other comments: Further research into improved diagnostics.

P244	Affected Comment: My husband at ***** was diagnosed with Stage 2 Prostate cancer and had a radical prostatectomy. It was only a chance visit to the GP that prompted a PSA test and then he underwent a series of other diagnostic tests to finally confirm he had cancer. Had it gone undetected there would have been a significant risk that the cancer would have spread outside the prostate Evidence Comment: More evidence needed to determine the speed of the growth of any cancer in the prostate Discussion comment: How do men know if they have the BRCA gene? Recommendation comment: I think screening should be recommended – too many men are dying Alternatives comment: Greater awareness of symptoms, better explanation of the side effects of surgery and how to overcome them
P245	Affected Comment: It has affected friends who would most likely be dead if the cancer hadn't been stopped & operated on. If there had been routine testing then it would have been caught much earlier & surgery been much less invasive & life changing Evidence Comment: Routine testing for at least those at risk of the cancer would catch far more cases at an earlier stage giving more men the chance of earlier, less invasive, less life changing (for them & their partners) treatment. Not picking up this cancer earlier means more costly treatment & much poorer outcomes. This is the wrong decision! Recommendation comment: Yes it should be recommended. Alternatives comment: Better to find the cases through screening than treating more men at late stage disease. Other comments:

	Think again. What if it was your father, brother, partner who could have been saved???
P246	Affected Comment: After poor treatment over a period of years by my local NHS urology department I was eventually diagnosed with ***** prostate cancer with metastases. My prognosis is terminal. I have a ***** year old son. I do not understand why the NSC will not allow him to have the chances of early diagnosis denied to me. Discussion comment: Reverse the decision to not include family members of prostate sufferers Recommendation comment: Screening should be recommended. Had it been available five years ago then maybe I would not be in this situation now and, through, my treatment, costing the NHS a fortune. Alternatives comment: Develop and make readily available cheaper self testing kits.

P247	Affected Comment: I am ***** year old male. I have a good friend from my school days He was recently diagnosed with early prostate cancer after unrelated tests his prostate was removed and as I understand is now cancer free thanks to early discovery of the disease. Testing is vital as I understsnd 10,000 men die every year in uk. I am going to try for a test ASAP. My frienf had no symptoms before the cancer was discovered by accident !
P248	Affected Comment: Had our GP surgery not called my husband in for a follow-up blood test, *****months ago, he'd most likely be receiving palliative care by now! A simple blood test showed his PSA score of *****...luckily our surgery were responsive to this& called him in for another to be sure. This 2nd test and physical test showed no concerns, but to be on the safe side he was referred for biopsy. Every ***** of those biopsies showed he had prostate cancer. He had no symptoms! He had a prostectomy (the cancer was contained within the prostate – thankfully it hadn't spread) Fast forward to today, his most recent PSA results show less than 0.01..so he's cancer free As his wife, as the person on the side lines seeing this man you love waiting for results, going through the trauma of treatment. It's as painful for me as it is him. Now, if he hadn't had any testing done..I'd be dealing with losing my darling husband, because noone had picked up this disease by a simple blood test. It essential routine screening for men over 40, we women have our routine screening for cervical cancer.. breast cancer. Men should have this annual blood test to ensure they are aware of their scores and they are monitored annually. Evidence Comment: I feel that their evidence is probably,far more technical and clinical than my actual life experience. However, this is men's lives we're talking about. Ok there might be some 'corrupted' incorrect results, but don't we get those with cervical screening? Far better to test and explore than ignore! Discussion comment: My last sentence in the previous question says it all It's far better to explore than ignore! Which is the current state of affairs for men. An annual blood test to screen PSA results, in the same way cervical screening (albeit that has been reduced from annually and age related!) is a benchmark for women and girls against cervical cancer.

	Again I'll say it Better to explore than ignore. Recommendation comment: Screening should be recommended. Better to explore than ignore! Men deserve to have a choice, women choose whether or not to have a cervical screening or breast screening...it's there for them. Men currently don't have that choice Alternatives comment: Knowledge is essential, my husband was given information by our trust and access to the cancer nurse, who was able to give advice. He was very lucky. Not every hospital uses the same procedure. Our friend lives in *****, he was offered the same options that my husband was...he was told that they didn't remove the prostate! Whereas here in ***** my husband had a choice. NHS trusts should all offer exactly the same treatment, it shouldn't be a Postcode Lottery! Other comments: All NHS trusts should have the same procedures to offer to patients irrespective of postcode...as mentioned before. We live in ***** and my husband was offered a choice of treatment, our friend lives in *****, he was told what treatment he should have, he wanted removal of his prostate (he'd seen how well my husband was treated here in ***** and felt confident he would receive the same in *****), he was denied this they told him that wasn't on offer as they preferred the hormone treatment first. He went private in the end as his scores were *****!

P249

UK NSC secretariat

Thank you for your reply to my previous email asking whether any other more advanced PSA tests had been considered to improve the admittedly low level of accuracy of PSA testing.

Clearly the reports that you refer to from Sheffield university are enormous in length and very hard to go through in any detail.

However having asked my phone to search for PSE, which is one of the advanced tests, in the Sheffield report it came back with zero mentions for PSE.

It would appear therefore that the modelling that you have had carried out to help you come to the decision on prostate screening, has not modeled any of the new much more accurate tests that are now available.

Are you really comfortable that it would appear you are going to recommend refusal of generalized testing for the population on the basis that PSA testing is so inaccurate, without considering whether much better results would be achieved if the more accurate newer PSA tests were used instead.

Surely you should be urgently recommending that detailed trials are carried out using these newer methods of assessing PSA augmented with genetic testing rather than shutting the door on a testing program based on such incomplete evidence.

Dear *****,

Thank you for your email.

The documents out for public consultation include the SCHARR modelling report - they can be downloaded from the UK NSC prostate cancer screening recommendation webpage [\[link\]](#) (click on the grey 'view documents' button at the top of the page).

You can also access the documents via the UK NSC blog post [\[link\]](#) regarding the consultation.

Kind regards,

UK NSC secretariat

Why does the Screening Committee not mention the more advanced PSA test such as the PSE test which moves the accuracy up to over 90%?

Everyone knows the PSA Test is unreliable but why can't it be replaced by the more advanced tests that have a much higher accuracy

To say that we shouldn't use PSA testing as a routine screening when much more accurate tests are available seems perverse.

Why doesn't the committee mention or recommend these more accurate test as an alternative?

P250	Whenever I have blood tests I always ask for my PSA and CRP (C-Reactive Protein) to be checked. In my professional life as ***** my main concern was could prostate problems be causing urinary tract obstruction contributing to kidney damage. On about 4 occasions, obstruction to urine flow was detected and following other investigations, prostate cancer was diagnosed. Yesterday I completed my work on Prostate Cancer for my next book "*****" and checked on the internet to see if there was new information. I was pleased to learn that the Transform Trial will be starting soon and the Barcode 1 study has been completed (page 261). I hope the UK National Screening Committee (UKNSC) finds the work useful. The father of one of my neighbours, when I lived in ***** sadly passed from disseminated Prostate Cancer at the age of *****. I now live in *****. I am in favour of screening for Prostate Cancer. A variety of factors need to be considered. There will be an e-book and paper format version of the *****. It is not a comprehensive Medical Textbook, but will focus on a variety of medical conditions that can affect anyone, other historical information is included: *****

P251	Further to my earlier email detailed below, it is with candescent anger and extreme annoyance that I am emailing you after hearing you have decided not to implement a prostate screening programme. I do not in any way agree that it would cause more harm than good; I do not hear that being said about any of the myriad cancer screening programmes for women. I can only conclude that your decision is not based on clinical evidence, but more likely on the monetary cost of such a programme being introduced as well as a what can only be deemed as a gender-biased attitude. As an example what the future will now hold based on your degusting decision, purely by chance I ran into a woman I know today who told me about her husband who has been diagnosed with terminal prostate cancer, despite being told there was nothing to be concerned about by his doctor as his PSA test was low. It was only after informing said doctor, much later, that he had the telltale signs of urination problems coupled with an urgency to go to the toilet, that he was sent for a MRI scan which showed his prostate was cancerous and had migrated to his bones ... too late !!! A prostate screening programme would have spotted his cancer in its early stages and he would not now be dying. Your decision has sentenced a great deal of men to death. I hope you are proud of yourselves. ***** From: ***** Subject: Fw: UK Prostate Cancer Screening NHS to offer same-day prostate cancer diagnosis - BBC News With reference to prior correspondence on this subject, above is a link to an article on the BBC News website. One particular paragraph is edifying : "Around one in eight men will develop prostate cancer in their lives, according to Prostate Cancer UK, with research showing it has overtaken breast cancer as the most commonly diagnosed form of the disease in the UK." This needs to be part of your process of reviewing the evidence for prostate cancer screening. It is now the most commonly diagnosed form of cancer in the UK and, therefore, there is no excuse for not introducing a prostate cancer screening programme in the UK. Failure to do so would confirm the view that men's lives are considered to be less important than women's and, in terms of gender equality, that is unacceptable.

From: *****

Subject: Re: UK Prostate Cancer Screening

Dear *****

Thank you for your email. Apologies, as it appears that our previous reply may not have been clear enough.

We were simply seeking to explain that the UK NSC's existing (current) recommendation is based on a review of the evidence that was conducted in 2020 (when it was found that the best test available at that time, PSA, could be unreliable, leading to false positive and false negative results, which can lead to unnecessary, potentially very harmful procedures, or missed diagnoses).

The UK NSC is now in the process of reviewing the evidence for prostate screening again. It is looking at the latest high-quality evidence and will go out to public consultation on this in due course.

Kind regards,

UK NSC secretariat

The UK National Screening Committee is hosted by:

The Department of Health and Social Care

39 Victoria Street, London,

SW1H 0EU

E: UKNSC@dhsc.gov.uk<<mailto:UKNSC@dhsc.gov.uk>>

From: *****

Subject: Fw: UK Prostate Cancer Screening

***** Thank you for your reply.

Your reply states:

"The UK NSC does not currently recommend screening for prostate cancer. This is because the latest review suggested that the best test available at the time, prostate specific antigen (PSA), can be unreliable, leading to false positive and false negative results, which can lead to unnecessary, potentially very harmful procedures, or missed diagnoses".

This is a spurious response, as the PSA test is not the only method for checking for prostate cancer.

Other methods are: CT scans, PSMA PET-CT, MRI and ultrasound to facilitate early detection and accurate diagnosis of a range of prostate conditions.

These are currently offered by non-NHS medical providers, so I do not see why any one or all of these methods cannot now be utilised in an NHS UK prostate cancer screening programme.

The statement: "The UK NSC is currently in the process of updating its position" must include one or all of the above testing methods as part of said process before a screening programme is (as it appears always to be) routinely denied to UK men, most likely based solely on cost; a disgraceful situation.

Think again please.

From:*****

Dear *****

Thank you for your email.

The UK National Screening Committee (UK NSC) only recommends a screening programme if high quality peer-reviewed evidence shows that the benefits of screening would outweigh any harms for the groups of people who would be offered screening. This is the case for the UK NSC's evidence-based recommendations for the 4 existing national NHS cancer screening programmes – bowel, breast, cervical and lung.

The UK NSC does not currently recommend screening for prostate cancer. This is because the latest review suggested that the best test available at the time, prostate specific antigen (PSA), can be unreliable, leading to false positive and false negative results, which can lead to unnecessary, potentially very harmful procedures, or missed diagnoses.

The UK NSC is currently in the process of updating its position based on the available evidence. In due course it will go out to public consultation on that evidence before making a recommendation to ministers. Ministers will then make a policy decision.

Kind regards,

UK NSC secretariat

The UK National Screening Committee is hosted by:

The Department of Health and Social Care

39 Victoria Street, London,

SW1H 0EU

E: UKNSC@dhsc.gov.uk<mailto:UKNSC@dhsc.gov.uk>

[A group of blue circles with black text Description automatically generated] [A black background with a black square AI-generated content may be incorrect.]

From:*****

I have read this BBC News article with great interest and heard the media rumour that there will be no change in terms of having a UK prostate cancer screening programme for men.

Research I have undertaken shows that around 12,200 UK men die of prostate cancer each year.

UK women who die of breast cancer is around 11,200 each year and UK women who die of cervical cancer is around 890 each year, but screening programmes for each type of cancer do exist for UK women.

This means that, in total, 12,090 UK women die of both types of cancers each year; this is only slightly less than the prostate cancer deaths for UK men, yet no UK prostate cancer screening programme exists !!!

How can this be justified ?

Are men's lives so much less important than those of women ?

The lack of a UK prostate screening programme for men could be construed as sexism and/or gender inequality; such inequalities are enshrined as unacceptable within UK law.

I totally support Mr Sunak in his pursuance of a prostate screening programme for UK men and it is incumbent upon your committee to uphold UK equality laws and enact its introduction forthwith.

P252

Dear UK NSC Secretariat,

Thank you for your response and for clarifying the status of the public consultation on prostate cancer screening.

I welcome the opportunity to contribute formally to the consultation process.

Given the significant and well-documented disparities in prostate cancer incidence and mortality among Black men in the UK, I believe it is essential that the Committee carefully considers the implications of the current draft recommendation through an equality and health-inequalities lens.

Yes, please include the comments from my original email as part of the ongoing consultation.

If needed, I am happy to provide an expanded version or additional evidence to support the Committee's review.

I look forward to the outcome of the consultation and the subsequent recommendations to ministers in 2026.

Kind regards,

From: *****

Subject: RE: Addressing Health Inequalities in Prostate Cancer: The Case for Targeted Screening for Black Men

Dear *****,

Thank you for your email.

Just wanted to clarify that the UK National Screening Committee has opened a public consultation on screening for prostate cancer and is currently taking feedback on the updated evidence on prostate cancer screening and its draft recommendation

Details of the consultation, along with the consultation documents and instructions on how to provide comments, are available via the UK NSC blog.

Responses to the 12-week consultation will be reviewed to determine if changes are needed to the evidence review or draft recommendation.

The UK NSC expects to make a final recommendation to ministers following the next committee meeting in March 2026. Ministers will then decide whether to accept the recommendation.

Please let me know if you would like me to include the comments in your email as part of the ongoing consultation.

Kind regards,

UK NSC secretariat

From:*****

To: UK NSC Inbox <UKNSC@dhsc.gov.uk>

Subject: Addressing Health Inequalities in Prostate Cancer: The Case for Targeted Screening for Black Men

Dear Members of the UK National Screening Committee,

My name is *****. I am a *****.

I am writing to raise urgent concerns about the exclusion of Black men from national prostate cancer screening recommendations, despite extensive evidence demonstrating that this group faces the highest incidence, earlier onset, and disproportionately higher mortality from prostate cancer.

1. Context: Disproportionate Burden of Disease Among Black Men Numerous studies establish that Black men in the UK: - Are twice as likely to develop prostate cancer (Prostate Cancer UK, 2023). - Are twice as likely to die from the disease (Public Health England, 2021). - Are diagnosed younger and often at later stages (Ben-Shlomo et al., British Journal of Cancer, 2008). - Experience systemic barriers to early diagnosis (Madgett et al., Lancet Oncology, 2021).

2. Risk of Structural Inequity Under the Current Screening Policy While concerns about PSA test precision are valid, applying uniform criteria across all demographic groups fails to reflect substantial risk disparities. This blanket approach disproportionately disadvantages Black men and undermines commitments to health equity within: - The Equality Act 2010 (Public Sector Equality Duty) - The NHS Long Term Plan - Core20PLUS5. Under Section 149 of the Equality Act 2010, public bodies must: a) Eliminate discrimination b) Advance equality of opportunity c) Remove or minimise disadvantages linked to protected characteristics. The current prostate cancer screening position does not demonstrate adequate compliance with these duties.

3. Evidence Supporting Risk-Stratified Screening Emerging clinical evidence indicates that improved diagnostic accuracy can be achieved through: - Combined PSA + MRI-based screening pathways (PROMIS Trial, Lancet 2017) - Risk-stratified screening incorporating ethnicity and family history (Martin et al., JAMA Network, 2022) - International comparisons where guidelines include higher-risk ethnic groups (US Preventive Services Task Force, 2018)

4. Recommendations to the UK NSC I respectfully request the Committee to: 1. Conduct a formal review of ethnicity-specific evidence on prostate cancer risk. 2. Commission targeted screening trials for Black men and other high-risk groups. 3. Publish a comprehensive Equality Impact Assessment (EqIA). 4. Develop a pilot risk-stratified screening programme. 5. Improve targeted communication encouraging Black men aged 45+ to seek early PSA testing.

5. Conclusion Failing to address the well-evidenced increased risk among Black men results in preventable harm and perpetuates entrenched racial health inequalities. The UK NSC has an opportunity to demonstrate leadership by creating a fairer, evidence-based screening framework that meets statutory equality obligations and advances early cancer detection for all.

I welcome the opportunity to discuss this further or contribute to future consultations.

	Yours sincerely *****
P253	I feel that if screening had been in place each year for the over 45's the prostate cancer I was diagnosed with would have been found before it had spread from the prostate. I was diagnosed with this cancer at the age of ***** in *****, it had spread to just outside the bladder. A date was set to carry out a prostatectomy in ***** that year, unfortunately I contracted *****, the procedure was put back a number of weeks which I believe allowed time for the cancer to spread further making it necessary to remove part of the bladder as well as the prostate. The procedure was not 100% successful, a ***** week course of radio therapy was carried out ending *****. If the cancer had been diagnosed earlier it may have only required "watchful waiting" at that time with a less invasive treatment started when it had progressed, negating the really nasty side effects of removing not only the prostate but also lymph node's, seminal vesicular and part of the bladder. Early diagnosis and a less invasive treatment could possibly have saved the NHS a lot of money being spent on the radio therapy, subsequent medication and a lot of heart ache for not only me but also my close family.

P254	***** To the UK National Screening Committee, I am submitting this statement in response to the current consultation regarding prostate cancer screening. I come from a family where prostate cancer has already claimed a life — my father. His cancer was detected too late, after spreading outside the prostate. Because of this, I was acutely aware of my own risk. A PSA test performed abroad detected a slightly raised level, which led me to pursue a specialist referral. This resulted in timely diagnosis of prostate cancer at a treatable stage, and I subsequently underwent curative brachytherapy. My concern is that men like me — with strong family history and higher genetic risk — may not take the initiative to request PSA testing, especially if screening programmes do not proactively encourage or support high-risk individuals. By the time symptoms appear, it may be too late. I strongly urge the Committee to consider: • A targeted, risk-adapted screening strategy, especially for men with family history. • Maintaining clear pathways for GPs to recommend PSA testing for high-risk men. • Ensuring that the new guidance does not create barriers for men most at risk of late diagnosis. My own life was likely saved by early PSA testing. I hope future guidance will protect others in similar circumstances. Sincerely, *****
P255	Dear Sir/Madam, the diabolical decision today to decide not to make prostate cancer, a mandatory screening programme, will cost lives. As men do not routinely go to the GP for an examination. They have to be encouraged. I'm sight impaired, and therefore vulnerable anyway. I have voluntarily been for an examination. And will do in the future. Men in there 60s as I am already have slightly enlarged prostates, which are common. This is why they must be screened as a mandatory yearly screening.

	This is completely the wrong decision. And I urge you to rethink this immediately. This has the capabilities to spread through the body. And not only ordinary citizens can be affected, but celebrities too! Meaning men whoever they are within society. Will be impacted from this type of cancer.
P256	Good morning. I would like to make a suggestion regarding above. Until national screening becomes avail. Would it be an idea to have workplace screening for. men? In partnership with royal mail. My husband works for royal mail which is predominantly a male workforce. Many of them work 6 days a week. They either have no time to visit a surgery and or are scared/too proud to. One day of workplace screening would catch a good cohort, with such criteria as age, family history, symptomatic. Either with a van in car park or base at depot. Good chance to promote awareness? Could name it DELIVERING RESULTS? Photo op with employees with sleeves rolled ul. Just an idea 🙏
P257	Discussion comment: This is a killer disease and you need to protect all men from this. Please approve national screening. Recommendation comment: This needs to be a national screening to save lives.
P258	Affected Comment: I was diagnosed with prostate cancer in ***** aged *****. No family history. Early diagnosis saved my life. There should 100% be a screening programme as others are not as lucky as I am. Evidence Comment: PSA test was the 1st indication for me. I had no symptoms. Random blood test that I asked for & was nearly denied. Recommendation comment: Yes it should be recommended to save men's lives. Blood on the hands of those that say PSA test can over diagnose. It saved me. Alternatives comment: If it is down to cost, set an age that screening can happen that is over 55 & make it voluntary but available for those younger.

P259	Affected Comment: Yes I was diagnosed with prostate cancer ***** years ago. As a ***** year old asymptomatic white male. Evidence Comment: The NHS was no help – if not for BUPA well man I would not have been tested. My life was saved! Waiting and watching it waiting for symptoms is not the answer. Discussion comment: I used to teach ***** – they are helpful but not the complete answer. The 12,000 annual deaths could include any of us. Men are cheated by this reluctance to intervene. Recommendation comment: It definitely should be offered from age 45. The trajectory of PSA is critical and the level is less significant the “delta”. Other comments: Make sure higher risk ethnic groups are represented in any trials

P260	Affected Comment: Yes it has in ***** and was picked by luck with just a visit on another matter at my doctors. No symptoms, just the Dr saying while you are here, let's just check.. and something was found and then on to treatment. Evidence Comment: This cancer can have no symptoms and therefore can be found too late in a man and needs to be found quickly so it can be dealt with. Discussion comment: Recommend mandatory testing from 50 years old for all males. Recommendation comment: Should be recommended as will save lots of lives for something that affects a lot of men from an early age of adult life. Alternatives comment: It has to be found first to be dealt with and that's the problem, we need a system to find it! Other comments: Introduce mandatory testing as soon as possible like that of women's breast cancer.

Affected Comment:

Yes, I was found to have raised PSA levels in ***** but I have remained positive and importantly pro-active in my treatment.

Evidence Comment:

As someone identified with a raised PSA level in ***** and opted for Active Surveillance at my local hospital in ***** until in ***** when I was referred to the prostate consultant in ***** who then sent my details to ***** as a potential candidate for focal therapy.

Short version I had targeted cryotherapy in ***** , I have zero unwanted side effects my post-operative mpMRI scan showed an excellent result and my PSA results are down from ***** to *****.

What really annoys me is the dire warnings I keep seeing such as the screen shot from a BBC report:-

***** , who is a urological surgeon in ***** , told me: "The diagnosis of prostate cancer in a healthy man is a hugely disruptive event – with potential to affect quality of life, very significantly, for many years.

"It cannot be done lightly, men need to be really well counceled and informed before the 'snowball' starts.

"Before you know it, you are on the operating table having yoyr prostate removed – and we see examples of this all the time, "***** said.

Statements like this really are flying in the face of current best practice and will deter many men from even considering having a test.

From my own experience there have been dramatic advances in screening and treatments in the last twelve years yet the reasons given for not recommending a screening programme are based on the historical scenarios, so point by point:-

Yes the PSA test is not reliable as a single reference point to determine any treatment but it is quite good as a starting point for deciding if further tests are needed. The newer mpMRI scans really can identify any problem areas very accurately.

The next stage to identify the "grade" of any potential cancer is a biopsy and this is very important as some are aggressive and fast growing but others, as in my case, are the 'just a bit lazy and can't be bothered' sort but need monitoring.

The method of taking biopsies has also changed as using the old rectal route could cause sepsis or other complications. The newer transperineal biopsy is, and I have experienced both, a much better method.

Finally, and this is the most important bit, the report keeps repeating the warning about the potential unwanted side effects of the treatments. Yes the removal of the prostate comes with risks but even ***** has a Da Vinci robot for surgery, it is capable of very fine control and should reduce unwanted side effects. But the whole point of screening is to catch the problem early and

there are a whole range of 'focal' therapies which are much less likely to cause unwanted side effects as I am one example of this.

Discussion comment:

The report UK NSC Rapid Review Screening Prostate Cancer Final February 2021 which is referenced was done in 2020 and procedures and treatments have improved since then but it criticises the PSA test because it can give false negatives but so do breast and cervical cancer screening and they also give false positives but mpMRI scans and biopsies can correct these errors before you are on the operating table having your prostate removed. Importantly screening can and does enable appropriate improved treatments to be initiated before it is too late.

I do not want to be an exceptional case, I want my treatment to become standard practice.

Recommendation comment:

Definitely yes, I was extremely lucky as my GP explained things very well to me and I was in at the start of the active surveillance programme rather than diving in with invasive and difficult surgery. Things have advanced dramatically do not let thousands of men die unnecessarily while you delay making the right decision.

Alternatives comment:

I am part of the "Biobank" study I know Prostate Cancer UK is doing the TRANSFORM study but there must be more that could be done with the Biobank data.

P262	Affected Comment: I was diagnosed with prostate cancer at age *****, only because i had a PSA test as part of a company medical. PSA was a little high, but i had zero other symptoms. A further PSA check resulted in an MRI scan, then a biopsy. Gleeson 8 in the results. My consultant predicted 5-10 years with no action. Opted for prostatectomy, histology showed some Gleeson 9, but all contained. So, I'm only still here ***** years later due to follow up from simple PSA screening... Evidence Comment: There seemed to be a lot made about 'men suffering from un-necessary treatment'. Surely the treatment after tests is almost entirely at the discretion of the medical profession? 'No action' is a valid decision in some cases. Seems like an excuse to me. Discussion comment: As above. Recommendation comment: It absolutely must be offered. Far too many men find out too late, because many have zero symptoms. Alternatives comment: Just start screening, please!!! Other comments: No, just start screening, thanks!!

P263

Affected Comment:

I was diagnosed with Stage 2/3 Prostate Cancer and underwent a prostatectomy late that year.

This cancer was detected by a PSA screening test as a result of routine screening of my PSA levels as I was prescribed with a testosterone gel following a ***** and hormonal issues.

Evidence Comment:

I am not an academic and find it impossible to analyse and comment on the document.

Discussion comment:

I think the conclusion and recommendations are wrong – I am of the opinion that PSA tests should be available to all males who fall into the age category.

Recommendation comment:

I think screening should be recommended. My prostate cancer was completely without any symptoms and I could have found myself with Stage 4 cancer if it wasn't for a PSA test. This horrible disease can be detected at an early stage with regular PSA screening

Alternatives comment:

I don't think there is any alternative to PSA screening.

Perhaps in the future, when genomic screening is drastically improved, then there may be alternatives but that is in the future – please deal with the present!

I am a great believer that early diagnosis is important and therefore we should perhaps fund other programs that may also capture early stage cancers of every sort.

Other comments:

I cannot see the justification for not screening males that are over 50. The cost to the NHS should not matter when you are talking about people's lives which you are. I am not naive enough to appreciate the logistics of PSA testing but, in my humble opinion and speaking from personal experience, a PSA test has almost certainly given me a chance to live a longer life.

I implore you to disregard this report's recommendations and continue and even extend the current PSA screening program so that this cancer can be detected and treated as mine has. Thank you for reading my comments.

P264	Affected Comment: I had no symptoms, no family history, white male aged *****. Random PSA test after seeing GP about unrelated issue. Result ***** MRI showed suspicious area. Biopsy showed ***** out of 20 samples cancerous, followed by bone scan which was clear. After much stress and anxiety opted for radical prostatectomy in *****. Between my MRI in ***** and removal in ***** the cancer had progressed from ***** to ***** meaning high risk of recurrence. PSA every 3 months for the foreseeable and every thing crossed. Recommendation comment: PSA is the best we have and may have saved my life, if you look at discussions on cancer websites I am far from alone.
P265	Affected Comment: Both my father and his oldest brother died from metastatised prostate cancer. In both cases it wasn't spotted soon enough to treat it adequately. The third brother is still alive though undergoing a lot of radiotherapy and chemotherapy. Evidence Comment: Due to the lack of evidence provided on black men this seems lacking. Recommendation comment: I believe, as a person with an increased risk of prostate cancer that screening should be provided. I don't want to find out too late that little can be done, and live through what my father lived through. I am a single parent of a 13 year old daughter. I am only allowed one psa test a year. I should be receiving more targeted screening and yearly MRI scans. Alternatives comment: At the absolute worst case, those with a higher chance of contracting prostate cancer, ie, parents who had it, or breast cancer. Or black men should receive frequent psa tests and at least a yearly targeted MRI. Other comments: Please don't pass on this opportunity to save lives.

P266	Affected Comment: Despite having no symptoms, not having a family history, and being of White British ethnicity, I received a PSA test in *****, with a follow up PSA test in *****. At the time I was ***** years old. This was as a result of my request to my GP for the blood test. The results were high. This was followed up with an MRI scan, showing localised cancer. I received a localised biopsy (***** samples collected), showing cancer to be present. This was followed up with a template biopsy (***** samples taken) that identified aggressive cancer. I was given the option of surgery (radical prostatectomy) or radiotherapy and hormone therapy. I opted for surgery. This was undertaken ***** weeks ago. As each stage the NHS has been brilliant. However, had I not requested the initial PSA test, I would be non-the-wiser in knowing that I have prostate cancer, and would not have been aware until it had progressed/advanced to be life threatening. Having been 'caught' early before breaking out of the prostate, means that I have received treatment that can 'cure' the cancer. Had there been a universal screening process in place, my would have been identified earlier. I consider myself to be fortunate in that the GP agreed to my initial request for a PSA test. I therefore propose that there should be universal screening for all men over 50 years, and screening for family members and members of certain ethnicities from the age of 45 years (as these have higher risks). Such universal screening would identifying prostate cancer earlier than would otherwise be the case, especially those without symptoms, like myself. As a result thousands of men's lives would be saved. Evidence Comment: The voice of those who show no symptoms but have been checked and diagnosed with aggressive prostate cancer is limited in the evidence gathered. I speak from experience that had I not requested, and that my GP agreed, to a PSA test, I would not know that I gave prostate cancer. Identifying the localised cancer means that early identification and effective treatment means that I am potentially cured, rather than not knowing and having it diagnosed, when it is life-threatening. Discussion comment: I believe that the conclusions are to limited in recommendations for screening. I therefore propose that there should be universal screening for all men over 50 years, and screening for family members and members of certain ethnicities from the age of 45 years (as these have higher risks). Such universal screening would identifying prostate cancer earlier than would otherwise be the case, especially those without symptoms, like myself. As a result thousands of men's lives would be saved. Recommendation comment: I believe that a universal screening programme should be adopted, this is based on my personal experience of being diagnosed with aggressive cancer this year.

I propose that there should be universal screening for all men over 50 years, and screening for family members and members of certain ethnicities from the age of 45 years (as these have higher risks). Such universal screening would identifying prostate cancer earlier than would otherwise be the case, especially those without symptoms, like myself. As a result thousands of men's lives would be saved.

Alternatives comment:

There is no current screening programme in place. The government should increase funding for a universal screening programme and increase NHS funding to treat patients who are diagnosed with prostate cancer.

Other comments:

I propose that there should be universal screening for all men over 50 years, and screening for family members and members of certain ethnicities from the age of 45 years (as these have higher risks). Such universal screening would identifying prostate cancer earlier than would otherwise be the case, especially those without symptoms, like myself. As a result thousands of men's lives would be saved.

I am pleased that NCS is engaging with the Transformer research project being undertaken by Prostate Cancer UK. However, I believe that this is also too limited to certain groups of men.

P267

Affected Comment:

My husband is ***** and has recently been diagnosed with prostate cancer ***** lesion risk of T3 disease.

He had vague symptoms of peeing more frequently in the evening.

No family history of prostate cancer.

The Psa test was back in ***** and We are now in ***** having just been told that the wait list for a radical prostatectomy is ***** months which is *****

Can you imagine the anxiety and stress this causing. If it were you and you had cancer wouldn't you want it removed at the earliest opportunity??????

Evidence Comment:

From the limited information I have only screening men with the a family history of BRCA gene variant will only be targeting 1% of the men diagnosed each year equates to 550 out of 55000. Where does that leave the other 54450?

Discussion comment:

My husband is not even going to be tested for the BRCA Gene variant, so where does that leave our 2 sons who are now ***** if screening doesn't commence.

Recommendation comment:

Screening must be recommended for all men over the age of 45.

I understand the implications of the PSA test but it is the best tool we currently have.

So it should be used for screening until a better more accurate test is found.

Alternatives comment:

I am not sure what alternative options there are. But what I do know is that screening saves lives.

My husband first had the PSA test in ***** and is now on the waiting list for a radical prostatectomy, which we have been told is a ***** waiting list, even though he is at high risk of disease progression There are no guarantees that it will not spread in that time.

This is a very stressful time in our lives and we do not know what the future holds.

If he had been screened earlier it may have been found and monitored earlier.

Other comments:

Yes screen all men from The Age of 45 using the current tools we have until Something better comes along.

Save lives

	Save your family Save your friends 1 in 8 men will get prostate cancer 10000 die every year 55000 diagnosed every year

P268

Affected Comment:

I requested a PSA test about ***** years ago having been diagnosed with Prostatism. At that time my PSA was approximately ***** but I requested a test annually and the PSA gradually increased until ***** years ago when it was ***** and I was given further tests which revealed early Prostate Cancer. I then had Cryotherapy to freeze the cancerous tissue. A follow up MRI a year later discovered that I cancer in my bladder which has been removed.

Without my insistence on PSA tests I'm not sure where I would be today!

Evidence Comment:

I think they are being very narrow minded!

Discussion comment:

I think they are being very narrow minded!

Recommendation comment:

I think screening should be offered to all males over 50, or younger if there are genetic factors.

Alternatives comment:

I don't see what else anyone can do without some sort of screening, even if it's different to the current PSA tests?

Other comments:

Promote research to obtain an accurate test for Prostate Cancer and offer it to all males over 50 or younger if required!

P269	Affected Comment: My father died of prostate cancer ***** years ago. I had urinary problems ***** years ago, a PSA test was done which showed a reading over *****. After a consultation and several more PSA tests the reading dropped below *****. I have done annual tests since, the most recent one being another elevated one despite having no additional symptoms Evidence Comment: The focus seems to be on how poor the PSA test is, which it clearly is, and on over diagnosis and unnecessary treatment. However, what it fails to note is that better approaches to elevated readings are evolving. With my father, more than ***** years ago, the approach was an untargeted biopsy. Now, an MRI is done which can help decide if any further action is needed and if it is, where to target the biopsy. Yes, the PSA test is poor (but no comments about developing a better test) but the follow up is much improved and getting better all the time Early diagnosis of potential problems is always crucial Discussion comment: It is a wrong conclusion based on out of date understanding of current methods A screening program is certainly needed and must be put in place Recommendation comment: Screening should be recommended. It is crucial to pick up this cancer before it spreads, PSA testing is a vital tool Alternatives comment: There is no current alternative to a screening program besides ignoring the problem and hoping it goes away...when it doesn't, all the NHS or government can then do is watch people die. Would you dare do the same for breast screening? Other comments: Ignore the findings of this review and implement a screening program now

Affected Comment:

I have Aggressive Prostate Cancer, diagnosed at age *****.

I am the primary carer for my wife, who had ***** in ***** , which was successfully treated following a ***** which left her with ***** , which is a better outcome than the alternative.

I was the primary carer for our son, who died of cancer in ***** , after his treatment was withdrawn at the beginning of the Corvid pandemic.

I have the BRCA2 gene, identified after my sister was diagnosed with breast cancer. Strangely she does not have the BRCA2 gene.

Evidence Comment:

1. The report only considered screening between the ages of 40 and 60. I was diagnosed with aggressive prostate cancer at the age of *****. Had there been screening up to the age of 71 (the same age as breast cancer screening) my cancer would have been pick-up at an earlier stage, and could have more treatable.

2. PSA is not very accurate the report did not consider other test options which are more accurate e.g. EpiSwitch PSE tests.

3. Prostate Cancer has no visible signs no lumps to feel or abnormal marks or blemishes to spot. Prostate cancer is hidden and silent. Relying on patients to identify possible symptoms and requesting tests is less reliable than a properly managed screening programme especially for a cancer where the symptoms are not obvious.

4. I have the BRCA2 gene, diagnosed ***** years ago, there was no follow up by the National Health Service. There is no means to screen or test everyone for these genes. If you did test everyone, a positive test could cause alarm; and lead to requests for preemptive surgery in the hope of avoiding cancer ; as some influential celebrities have. It is also worth noting just because you have one of these mutant genes it does not mean you will get cancer.

5. Late age (over 70) prostate cancer does not always mean it is a slow growing tumour. Unless you test the cancer to determine whether it is slow or aggressive you cannot be sure. Screening and identifying the type of cancer is important to save lives, doing nothing costs lives.

6. The report suggests that living with the consequences of invasive treatments is bad. However, living with the consequences of successful invasive treatments is far better than the fatal alternative, which this report advocates.

Discussion comment:

When considering the question whether or not screening for Cancer is worthwhile there are two questions to answer.

1. Can screening successfully identify cancer early?

2. Can the cancer be successfully treated?

This report findings show that 28 out of 1000 (2.8%) were identified with prostate cancer using the current PSA test. When you look at other cancer screening results e.g. bowel cancer

screening only 1.76% of those screened in England are identified and referred for further investigation. At 2.8% this report indicates that screening would successfully identify those with possible prostate cancer. Using improved tests will only increase the success rate.

The report also points out there is a very high success rate for treating prostate cancer when caught early.

However, the National Screening Committee report correctly identified that some diagnoses of prostate cancer have led to unnecessary treatments, of cancers which would have been better left untreated. This does not invalidate that screening can save lives.

What it does mean is that the threshold when treatments start needs to be better defined. I agree that small slow growing tumours should not be treated, but they do need to be monitored and identified as such. A friend of mine had such a tumour which was left untreated for years, but it was monitored. Then early this year there was a change, the change was picked up and he had a successful prostatectomy.

There is a well established process used by Doctors to determine the size and state of prostate cancer, called the Gleason scale. I am a***** or ***** on the scale, the highest score is a 10 (untreatable). So Doctors can identify which cancers which need treatment and which do not. This issue can be addressed by better defined thresholds for when treatments are required.

This report says screening can successfully identify cancer early and that prostate cancer can be successfully treated.

Unfortunately it recommends that no screening programme for all men as it is "likely to cause more harm than good". Why?

The likelihood of causing harm can be reduced by better guidelines on when to carry out treatment.

Screening can and will save lives.

The report has only considered the age band 40-60 the majority of prostate cancer diagnosis happens over the age of 60. In my case 71. testing should continue to the age of 70, to catch more cases of prostate cancer and save more lives.

Recommendation comment:

Yes I do think screening should be recommended.

Screening can successfully identify prostate cancer early.

Prostate cancer can be successfully treated.

The guidelines on when to carry out treatment on prostate cancer needs to be better defined to reduce unnecessary treatments and the likelihood of causing harm. Clinical guidelines are where this issue should be addressed.

The reason why more men die from prostate cancer than women from breast cancer is because there is no screening programme.

it is better to live with the after effects of treatment, than the fatal alternative.

Screening can and will save lives.

	Alternatives comment: No – Prostate Cancer has no visible signs no lumps to feel or abnormal marks or blemishes to spot. Prostate cancer is hidden and silent. Relying on patients to identify possible symptoms and requesting tests is less reliable than a properly managed screening programme especially for a cancer where the symptoms are not obvious. Before you can help people with the condition you need to be able to identify those with the condition, you need a screening programme then you can help them. Other comments: I am concerned about the recommendation to offer screening for those with BRCA1 and BRCA2 genes. You need to identify those with the genes, this will require a screening programme. Just because you have the gene it does not mean you will develop cancer. If you did test everyone, a positive test could cause alarm; and lead to requests for unnecessary preemptive surgery in the hope of avoiding cancer.
P271	Affected Comment: My husband was diagnosed with prostate cancer in *****, no symptoms, a very fit man, no family history. He asked for a PSA routine test and our GP also did a physical examination. His PSA was low but the examination found a lump on the prostate. After an MRI, biopsy and then removal of the prostate we were told that the cancer was significant and would have spread had it not been caught and removed. So without a test my husband would almost certainly have died, a husband, father, grandfather, brother and friend would have been lost, so many lives affected. Discussion comment: Screening should definitely be offered, and MRI scans and biopsies to confirm if cancer present if the PSA test and physical examination show there is a problem. Recommendation comment: Without a routine test my husband would have died, how many men should die like this? Other comments: Please think how you would feel about this if your loved one died of prostate cancer due to the lack of testing.

P272	Affected Comment: Although I have not personally experienced prostate cancer, I have seen friends, family (including my father) and close work colleagues diagnosed at advanced stages, often after opportunistic testing rather than organised screening. The human and economic costs of late detection – including aggressive treatment, loss of productivity, and long-term morbidity – underscore the value of earlier detection strategies. These lived experiences inform my concern that current policy fails to provide equitable preventive care for men, especially compared with long-established women's cancer screening programmes, despite prostate cancer being the most common cancer in men in the UK Evidence Comment: The evidence review reflects a narrow focus on PSA testing and modelling of its clinical and cost-effectiveness. However, this framing underrepresents important developments in prostate cancer diagnostics – such as risk-stratified screening pathways that combine PSA tests with MRI imaging and other risk factors – which have the potential to materially improve the balance of benefit and harm. There is also insufficient consideration of evidence outside strict trial designs, such as real-world data showing that opportunistic early detection (e.g., via PSA plus imaging) can catch aggressive cancers earlier and reduce mortality. Moreover, the inequality in how screening evidence for prostate cancer is weighed compared to women's cancers (e.g., breast and cervical), where imperfect tests were adopted into routine screening with phased refinement over time, suggests an incomplete evidentiary baseline. Discussion comment: The draft recommendation to limit screening to men with confirmed BRCA1/2 gene variants is a step in the right direction but too narrow in scope. It excludes groups known clinically to be at higher risk – such as men of Black African or Caribbean heritage and men with a family history of prostate or related cancers – without clear justification beyond conservative modelling thresholds. Evidence of disparities in diagnosis and outcomes argues for a broader risk-stratified approach rather than reliance on genetic status alone. The conclusion also overemphasises potential harms of screening without sufficiently weighing the harms of late diagnosis, which include advanced disease management, poorer survival, and diminished quality of life. Recommendation comment: I believe that some form of risk-stratified prostate cancer screening should be recommended. A national screening programme need not be a single PSA cut-off applied uniformly; it should integrate current best evidence on multi-stage diagnostics (e.g., risk scores + imaging), and be piloted at scale to refine selection criteria and reduce overdiagnosis. Other national cancer screening programmes have adopted similar phased strategies, balancing benefit and harm while reducing inequalities in access and outcomes. Not recommending any organised screening perpetuates a systemic inequality in cancer prevention for men compared with women, and fails to align policy with emerging evidence and diagnostic capabilities. Alternatives comment: Alongside risk-stratified screening, the NHS should: Provide consistent, accessible risk information for men and clinicians to facilitate informed, shared decision-making about testing.

	Expand education campaigns on prostate cancer risk factors, symptoms, and early detection, similar to existing women's cancer awareness campaigns. Invest in primary care training and tools to help stratify individual risk profiles using a combination of age, family history, ethnicity, and diagnostic advancements (e.g., MRI, novel biomarkers). Support regional pilot programmes that gather real-world data on newer screening protocols, to inform future national roll-out and refine cost-effectiveness analyses. This broader package recognises both the need for prevention and the limitations of any single test. Other comments: I recommend that the UK NSC explicitly incorporate gender equity criteria into its final appraisal framework. This should include comparative analysis of how screening uncertainties are treated across male and female cancers, and how existing diagnostic pathways might evolve into effective organised programmes. Additionally, the committee should commit to regular interim updates of its recommendation as evidence emerges from ongoing trials (e.g., TRANSFORM) and advances in imaging and multi-marker risk assessment. This proposal would align prostate cancer screening with broader NHS preventive health objectives and ensure that decisions reflect both scientific evidence and ethical commitments to equitable care.
P273	Affected Comment: I am currently being monitorind for prostate cancer.. The decision to remove this is sentencing men to a death sentence Evidence Comment: This stupid decision is to save money..As the most results are negative, look at the numbers found by the screening. Recommendation comment: see above Other comments: The Government are due elections in 2026 and later at the end of this parliament.. The votes they get will depend in my case whether we vote for thm !!

P274	Affected Comment: Having ***** brothers die of metastatic prostate cancer (white British) and no family history, I feel the decision to limit testing is unacceptable. There is no such thing as over testing. Evidence Comment: The cost of prevention is always more expensive than cure. However, the current situation is not acceptable as the cost of treatment, palliative care etc is costly. Recommendation comment: Screening should be recommended for the reasons above. Men should be given a chance, even though the current screening is not good. Alternatives comment: If there are alternatives to screening, why aren't they being used? Other comments: Just do it!
P275	Affected Comment: I am ***** and very healthy and fit. ***** years ago I went to the doctors about a ***** which had ***** and whilst there I requested a blood test as a year earlier my best friend had been diagnosed with prostate cancer. I had NO symptoms or family history. The PSA can back at ***** and I then went through the process of another PSA test, again *****, MRI scan and biopsy which confirmed a Gleason of ***** and a ***** diagnosis. I had a ***** and the pathology came back with a ***** but not metastatic. Evidence Comment: I cannot see why the experts don't read evidence of the no symptoms that I hear from my friends who have been diagnosed with the disease. It seems a lottery that you can only win if you request a check. Discussion comment: How would I know if I have a DNA/genetic mutation as I wouldn't know how to get checked or even know that you can get checked out. Recommendation comment: I feel extremely strongly that I and my best friend would be at stage 4 cancer now if we hadn't done a request screening. It was more luck that we caught it when we did and had treatment which provided a CURE. Other comments:

	Symptoms are hidden or non existent so having a cheap and quick blood test is the only staring point for what I perceive the only way forward, the automation of blood tests with the advances in AI is needed and then a pathway to establish the correct way forward to manage the prognosis.
P276	Affected Comment: Yes and watching a loved one die from cancer is hellishly traumatic and inhumane, particularly in those final days where the suffering, fear and physical decline is harrowing to watch and deeply cruel to witness and endure. Evidence Comment: Woman are regularly screened for cervical cancer from age 25. There is no similar national screening test for men and prostate cancer. Prostate cancer is significantly more common and causes more deaths than cervical cancer, Discussion comment: Prostate cancer is the most common cancer amongst males in the uk, particularly advanced stages. Prostate cancer often has no symptoms until advanced, and this is why better screening strategies are required. Recommendation comment: Yes, prostate cancer is slow growing and curable and if contained the survival rate is extremely high. Help Save our husbands, fathers, sons and brothers. Other comments: There should be a national psa screening test from age 25 every 5 years for all men.

Affected Comment:

It has affected friends, and distant relatives.

It affects me, because as a man I am at risk of dying from it, but I have no ability to prevent it or feel in control of catching it early.

Evidence Comment:

I think there was a failure to adequately consider advances in MRI scanning technology and how this influences the risk of over diagnosis, and the use of minimally invasive surgical procedures such as focal therapy for reducing side effects.

The cost effectiveness assessment fails to compare prostate cancer screening to breast cancer screening, which may be very similar in terms of cost effectiveness. Comparison to other screening programmes that are embedded in public expectation is very relevant when considering cost effectiveness.

Discussion comment:

I think all the members of the screening committee should have appeared publicly to present their judgements and take questions from the press and relevant stakeholders.

Recommendation comment:

Yes, screening should be recommended.

Roughly 4,000 men under the age of 75 die of prostate cancer every year, not significantly less than the 6,000 women under 75 who die of breast cancer.

Diagnosis and treatment can only get better if screening takes place.

Treatment is a choice – men should be allowed to make informed choices about their health and their bodies

Alternatives comment:

The average waiting time to start treatment (> 18 weeks) is a national disgrace and should be considered a national emergency to improve

DRE and TRUS biopsies are archaic, degrading, and dehumanizing interventions that should be abandoned in favor of 3T mp MRI and MR fusion trans peroneal biopsies

Far more holistic support therapies should be available to men with prostate cancer, including erectile dysfunction treatments, counseling, physiotherapy and support at home

Other comments:

Research funding should be massively expanded into better surgical approaches, differentiating between high and low risk cancers, and improving longevity in metastatic disease.

Home PSA tests can be purchased on Amazon for less than £10. If men genuinely do not deserve a screening programme funded by the NHS, then encourage men to do it themselves.

P278	Affected Comment: Yes, this decision directly affects me. I'm a Black man, ***** years old whose mother suffered from breast cancer diagnosis and treatment. Evidence Comment: I'm unsure how robust the data is for certain portions of the population, eg Afro-Caribbean communities. For instance, beyond my mother and father, my family of history of cancer diagnosis is unknown to me. This can be attributed to a broad cultural reluctance for families to discuss medical issues, further exacerbated by geographic issues. Both my father and mother relocated from the UK to the Caribbean. I have no day to day access to information about their medical treatment. I dare say this is quite different to a white British male or the same age as me whose parents are more likely to live locally (or, at least, still in the UK). Anecdotally, I am not aware of any data existing for anything beyond my parents, eg nothing for me grandparents who were born, lived and died in the Caribbean. Again, where there's no depth of data available to examine for my family, I'd expect far more data, at least one additional generations' worth (grandparents, if not, great-grandparents) for a white peer family in the UK. I'm not a clinician so not qualified to assess whether or to what degree familial health data might impact this research and the recommendations being made, but I have lots and lots of questions and every reason to fear – to a degree based on decades of institutional racism – that black men, to already identified as a high risk group, will be poorly served by a live away from blanket testing (bearing in mind, at the age of *****, I've struggled to get as many as one test per year since I was *****). Recommendation comment: I believe screening should be recommended. Whilst I respect the clinical views of those making the recommendations, I cannot concede, noting the likely lack of robust data on black familial cancer rates, that a move away from screening will impact all groups equally. Specifically, as black males aged over 50 are already deemed a high risk group it seems fair to conclude this same group suffers the greatest potential detriment by removing this one detection tool we have. Other comments: Demonstrate to the public that, at some level, whether it be anecdotal voices of the public or clinical voices of trained professional that due consideration both for the adverse physical and psychological impacts of this recommendation have been borne in mind.

P279	Affected Comment: It hasn't affected me so far but I do know many people who've been affected. Prostate Screening is essential particularly in men of colour because of the high incidence of disease as well as mortality. Screening can start now with the tools that we have. It can be improved in the future as more and more tools become available Evidence Comment: Increased evidence of prevalence in men of colour Discussion comment: Screening should start now in the population with high prevalence Recommendation comment: Should be recommended
P280	Affected Comment: I have several friends who are affected by prostate cancer, one currently undergoing treatment. A screening programme as per bowel cancer would surely help spot cases early.
P281	Affected Comment: Yes ... a friend of mine is diagnosed to have prostate cancer Evidence Comment: There is now stronger evidence on risk-stratified screening. This includes age, family history, ethnicity, PSA density, MRI, and genomic tools. These approaches may reduce overdiagnosis and overtreatment. Recommendation comment: I do support a targeted, risk-based programme. Evidence has improved since the last review. MRI before biopsy reduces unnecessary procedures. PSA density and repeat testing improve specificity. Risk factors such as age, ethnicity, and family history are well defined. The current "no screening" position is outdated. Universal screening is unsafe and inefficient.

	A risk-stratified national screening pathway is justified. I believe the UK National Screening Committee should recommend a formal review with this aim.
P282	Affected Comment: yes, My ***** died with it and never knew he had it until end of life. My dad was diagnosed ***** years ago at age ***** with stage *****, he had radiotherapy, surgery and the removal of his bladder as it had spread, I was diagnosed ***** years ago at age ***** after ***** years of increasing PSA results, I had a Radical Robotic prostatectomy. And now the ***** generation, my *****. We are now treading the same path. All my research from the day my dad told the family clearly showed the evidence regarding family links, this group is the highest risk, 1-3 sons or brothers will get PC. Over those ***** years nothing has really changed, the establishment appear scared of change, they are fixed with out of date data, values, views and beliefs. They seem not to have moved past the early 2000 views, values and attitudes. The arrogance is astounding, the listening is deafening, the acceptance to change glacial. what men need. 1. A National regularised testing programme, with sequential testing based on individual risk. Starting with all high-risk men.

2. Reconsider the single random PSA test (a test that we know has limitations) and millions is spent on further tests, just in case?? That's just not a logical or economic approach.
3. Remove the need for men to ask for a PSA test and start an invitation process on a risk-based approach.
4. Improve GP NHS guidance and upskill GP knowledge.
5. Currently there are contradictory threshold scores depending on which guidance the GP practice follows, NICE NG12 or the Prostate Cancer Risk management programme. Adopt a single approach.
6. All treatment plans need to be transparent and tailored to the individual with clear guidance via a multi-disciplinary team.
7. Improve age-related data, do men at different ages cope better or worse with different treatments and have outcomes?
8. Start a mental health care approach for men and their families that are diagnosed.
9. Start to evolve centres of excellence and reduce poor, costly local logistics
10. Start genomics testing for a better-informed cheaper treatment pathway.
11. Start Genomics testing for inherited risk factors that allows early detection

Evidence Comment:

The question being asked is naively narrow, mass screening yes/no??

A reframed question would be. Is mass screening a good approach or is a Risk based targeted model more optimal.

Why was the European Randomised PC data from the 2019 update not considered relevant. This data of nearly 200k men and 30 years gives a very clear scientific fact based argument that regular testing saves lives? The robustness of this data is much more empathic as each further review is conducted. As the data evolves with time it shows an increasing positive yes to screening, it saves lives.

The Stockholm 3, PSA, an advanced blood test using bio markers and 101 genetic markers into a algorithm to provide, personal, and grouped risk assessments. In the first draft for the NSC paper this was being considered and then dropped in draft 2, with some ambiguous wording around data. Why was this groundbreaking test dropped?

The key advantages of Stockholm 3 over traditional PSA

Higher accuracy distinguishing aggressive cancer from benign.

Reduces testing, MRI Scans and biopsies by 50%

Early detection of aggressive cancers at low PSA levels.

Delivers a personalised pathway.

For men aged 45 to 74

The 2025 evidence is virtually a repeat of the 2020 recommendation; it's a self-fulfilling prophecy and repeats the old message of rubbish in Rubbish out.

The data assumptions are flawed, does not clearly answer the question raised, but makes assumptions and assumption on assumptions to fit the NSC's historic and old fashion views and values, it shows a clear out of date bias in its narrative.

The same issue can be seen in 2020, but nobody asked the questions from the recommendation of how we get to the robust data required to clearly answer the question raised using data and reducing assumptions.

The NSC have glossed over 25 years of known facts regarding the family connections? And have mis represented the facts by using poor assumptions and hiding behind old fashion views. Clinging to what they understand and know, while maintaining the status quo by saying the data is not sufficiently robust. In any commercial sense, this would result in a recommendation of inconclusive, with a plan to close the information gap ASAP. It should never be a straight no, unless a preconceived narrative is desired.

The committee were not transparent in 2020 about the lack of robust data or made any recommendation of what data in required to answer the question asked. This is a circular argument that suites historic bias, views and opinion.

This is the same issue for Black men, insufficient robust data, not enough data, it's the same circular hold patten. the committee do not have enough robust data but refuse to recommend a limited trail to get that data??

This is called error management, The committee know errors have been made using old fashion values, understandings and beliefs. A narrative is built to prove the errors made, are correct via assumptions.

Discussion comment:

The 2025 conclusion was written in 2020 with the same bias. If you do not have robust data to answer the question then you need to say just that and not make any recommendation.

What do we know:

- 1-8 men will get prostate cancer (Moving to 1-6 Cancer UK data)
- 1-4 Black men will get prostate cancer.
- 1-3 High risk men will get prostate cancer.
- All men regardless of their prostate risk profile are treated the same.
- 12000 men per year will die from Prostate cancer increasing to 17500, Cancer UK data.
- We know prostate cancer is curable, if caught early.
- We know that early diagnosis is cheaper to manage, has better outcomes for men and saves lives.
- We know PSA testing is flawed, mainly due to the Radom one off, occasional test process.
- We know the NHS does not use sequential / risk-based testing

- We know PSA testing is cheap and does a respectable job.
- We know the NHS does not use PSA trend data for risk assessing prostate diagnosis
-

We do know that the NHS starts from ground Zero, or critical management. A man has a PAS test and the results could mean further expensive and intrusive tests, yet the one test result could be flawed, a known issue. This is not a good default start position.

Nobody is looking at risk profile or what "Good " looks like for each man. In other words what does this mans Risk to prostate cancer look like?

When you consider the Government has invested millions into the Transform project and the first major initiative is early diagnoses, you could consider that the NSC had to come up with this recommendation to allow Transform to deliver the "change the dial" moment and validate the investment.

This is probably the reason Stockholm 3 was written out after the first review.

I do hope that egos are not the issue that would cost 24000 men their lives whilst we wait on Transform.

Recommendation comment:

This is the crux of the issue and difficult to provide a simple Yes/No recommendation, with the Sheffield model used. This model is based on historic data, views, beliefs, values and assumptions.

It seems to have ignored the new improved processes, systems, like the MRI, MRIemp, trans perineal biopsy, active surveillance reducing the volume of low grade cancers being treated. If you add these into a risk based disruption model you get very different outcomes.

What does a good screening model look like:

- A Much-improved PC pathway needs to be developed.
- A Risk based approach for the whole population, starting at 45 for the highest risk groups.
- A personal risk assessment completed. The system must be self-learning or call it AI if you must.
- Following a risk assessment the population is tiered, very high risk, High risk, Medium and low. An initial PSA result recorded, to evidence what good looks like. Instead of placing millions into a funnel you are managing thousands.
- The risk-based model will determine the follow up time scales.
- Limit additional action from a single test, a further test a week or so later to account for the potential known issues. (All men must be given very clear advice of the dos and don'ts prior to the PSA test) At the test the man is challenged again to ensure they have complied with the advice.
- A sequence of PSA results tells a story, and it may not be cancer.

Now we get into the more Harms than good element of the historic bias.

. MRI scans have improved the need for unnecessary biopsies. But the scan needs greater definition to show, slow and aggressive cancers, the process needs more refinement or adopt Stockholm 3 which achieves a similar result.

. The trans perineal biopsy techniques have significantly reduced infections by around 90%

The improved interpretation of the PSA risk assessment data,

1) reduce the false positives,

2) leading to reduced numbers requiring scans,

3) leading to lower numbers requiring the improved Biopsies.

4) Leading to Earlier detection reduces the growing numbers of late diagnosis and improve outcomes.

5)Is cost effective, leading to far fewer numbers being diagnosed late and needing very expensive longer term treatment plans.

Leading to better outcomes for men.

Alternatives comment:

This is a silly question when you consider the topic.

Other comments:

Action Required.

The PC Pathway needs a full policy review, with a clear approach within timescales, Good, positive language. reflecting Culture and age variations and closing the discrimination gap.

A clear plan to capture all PC data.

Consider supporting a new charity to undertake the Risk assessment and PSA testing process with a clear hand off into the NHS.

1. A National Risk based regularised testing programme, with subsequent testing based on individual risk. Starting with high-risk men.

1a. To understand high risk: develop clear guidelines on family connections and Black men, Braca. The issue for Black men especially is the data shows they are the highest group to be diagnose with Stage 3/4 but there is no clear evidence to say if this is genetic or is it cultural, or is it the same discrimination as all men from low social economic regions?

2. Reframe the single random PSA test (a test that we know has limitations) but continue to spend millions on further tests, just in case?? That's just not a logical or economic approach.

2A. Start sequential PSA testing based on the risk profile of the man and two / three PSA results as they become available.

	3. Improve GP NHS guidance and upskill GP knowledge. Have just one set of policy documents and not the current two. 4. Remove the need for men to ask for a PSA test and start an invitation process at age 45 on a risk-based approach. (Start with what looks “good” and not crisis management) 5. Currently there are contradictory threshold scores depending on which guidance the GP practice follows, NICE NG12 or the Prostate Cancer Risk management programme. Adopt a single approach. 6. All treatment plans need to be transparent and tailored to the individual with clear guidance via a multi-disciplinary team. With all treatment options open, and not the current localised discriminatory approach depending on which hospitals have signed up for trials? (Trails, Data and success rates are a very separate but important issue) 7. Improve age-related data, do men at different ages cope better or worse with different treatments, recovery and outcomes? 8. Start a mental health care approach for men/families that are diagnosed. (Could be as simple as handing off to a charity) 9. Start to evolve regional centres of excellence and move to the gold standard within a reasonable timescale. 10. Start genomics testing for a better-informed cheaper treatment pathway. Especially for the highest risk groups and inherited risk factors that allows early detection TRANSFORM is publicly funded via donations and Government funds. The whole programme needs to be far more transparent than it currently is. I will be pushing for Judicial review.

P283	Affected Comment: Yes, prostate cancer has directly affected a member of my family, and it has deeply changed our lives. Watching someone we love struggle with this illness has been incredibly painful and has severely impacted their quality of life. Beyond the physical effects, the diagnosis brought ongoing emotional stress, fear, and uncertainty for our entire family. The financial burden of medical care, treatments, and missed work added another layer of strain, making an already difficult situation even harder. As a family, we have had to navigate not only the illness itself, but also the emotional exhaustion and challenges that came with supporting one another through it. Evidence Comment: All the evidence appears to have been accurately captured and correctly presented in the data. It would have been even more informative to see the distribution of other ethnicities as well, in order to assess whether the risk remains higher, as studies suggest, in Black males or whether this trend has changed over time. Discussion comment: None at the moment Recommendation comment: Screening services should be recommended, as they can be life-saving by detecting the illness early. However, these services should target specific populations rather than being applied to the entire population. As mentioned in the trial, issues like the risk of high false positives should be considered. Therefore, testing should be more focused and targeted to those at higher risk. Alternatives comment: Sensitization efforts to raise awareness of the signs and symptoms of prostate cancer should be innovative and creative, moving beyond traditional mainstream advertising that can easily be ignored. Approaches like interactive campaigns, digital storytelling, or using influential community figures could capture attention more effectively. These strategies can break through the stigma and encourage men to seek help, while fostering a sense of urgency for early detection and treatment. Other comments: None at the moment.

P284	Affected Comment: YES. I have prostate cancer. I had no symptoms or those I had I put down to age. Mine was aggressive, and had spread, fortunately not to my bones. Had an enlightened GP not done a PSA test I would be dead. Because of my condition friends have asked for a PSA test and their GP has refused. NOT A GOOD SITUATION I have a ***** year old son, I don't know if I have this bloody gene, or if he has without a test. THAT HAS NOT BEEN OFFERED Evidence Comment: It is better to know if a bloke has prostate cancer AND BE ABLE TO GET A TEST than live in oblivion all at the cost of a few pence. Discussion comment: Those who carried out the 'REVIEW' should get a proper job Recommendation comment: Screening should be available to everyone who requests it, despite the risks associated with biopsies etc. Alternatives comment: Such as what. A PSA test is better than nothing Other comments: Make the test available.

P285	Affected Comment: All the male line down to me have passed with cancers of various kinds so i am naturally on the alert as to what to do for the best... as and when it is my turn...so have had psa tests via Chaps and the NHS but it is yet a crude, basic affair and needs to be improved...so i support any improvements that can and must be made – i expect King Charles had the very best, latest tests and is having the best treatment – all this should be passed on for the general good not passed over... so please get on with it – in conjunction with AI of course !!! Thanks for listening Evidence Comment: The Desire to KNOW is great – the need is great – please supply the need Discussion comment: It is self-evident things need to improve for everyones sake Recommendation comment: YES – WHY NOT ? ! Alternatives comment: Go as you go, but just go – get on with it – thank you. Other comments: Where there IS a will, there IS a way Let us all be treated like Kings – not overly expensive, disposable peasants
P286	Affected Comment: No th affected me, however this condition has had an impact on a cousin. Early detection is a necessary. Alternatives comment: Implement screening
P287	affected Comment: My step father died when his prostate cancer had already spread. If he had a routine PSA test, this could have been prevented.

P288	Affected Comment: Yes. ***** very close friends who have had regular (annual or bi-annual) PSA checks since the age of ***** yrs old have then been diagnosed with Stage ***** prostate cancer in their early or mid *****. Evidence Comment: MRI scans before biopsies can significantly reduce the harms of unnecessary procedures and overdiagnosis. It seems the NSC have completely failed to properly consider the benefits of MRI scans. Meanwhile, women are provided with scanning, resulting in very good prevention and early stage treatment of breast cancer. Why can't men have the same? The conclusions of the report are fundamentally flawed – if PSA testing and digital examination fail to provide accurate results, then use a form of screening that works!! Discussion comment: MRI scans before biopsies can significantly reduce the harms of unnecessary procedures and overdiagnosis. It seems the NSC have completely failed to properly consider the benefits of MRI scans. Meanwhile, women are provided with scanning, resulting in very good prevention and early stage treatment of breast cancer. Why can't men have the same? The conclusions of the report are fundamentally flawed – if PSA testing and digital examination fail to provide accurate results, then use a form of screening that works!! Recommendation comment: Screening should be recommended. But it has to be effective screening. Use MRI, alongside an effective means of monitoring PSA levels. It's quick. It's cheap. MRI can provide a baseline against which the speed of any growth can be measured. It avoids unnecessary biopsies and it doesn't give false positives/negatives. Monitoring PSA alongside it gives a much more reliable screening option for men. Alternatives comment: Give men the choice that is available to women. Use a screening method (MRI, with PSA testing alongside) that is effective. Stop denying men access to effective screening and give them the option.

P289	Affected Comment: I had a radical prostatectomy in ***** after ***** PSA tests showed that I had a raised PSA for my age (*****). I only had the PSA test by chance after visiting my GP to get a mole checked for cancer. During that visit I mentioned to my GP about getting a PSA test as I had seen an article on the BBC News about newsreader Bill Turnbull having been diagnosed with PC. Tragically Bill died as his cancer had been found to late for treatment. I was lucky, my cancer was caught early enough purely by chance and I;m now cancer free and with the exception of***** I lead a full and normal life. Evidence Comment: I think the review missed how many men are living with PC but don't know that they have it – this removes their ability, after further tests and discussion with multi disciplinary medical teams to make an informed decision on what course of action to take. Screening could give them an important life line to have this condition caught early so that any treatment can make a positive change to their and their families lives. The earlier treatment can begin the better chance of getting back to as normal a life as possible with this cruel disease. Discussion comment: I think the recommendation is short sighted and does not take account of new and updated medical practices and focuses too much on historic data that is no longer relevant. A positive Prostate Cancer diagnosis is bad enough and affects a man's family and friends. What is worse is not having that diagnosis and being told it's too late – we can't do anything for you – it's terminal. Especially if they had been tested and the cancer found earlier. Recommendation comment: I think screening of all men over 45/50 should be recommended and my lived experience is exactly why. Had I not had that PSA test I would not have known I had cancer. I was given all the facts of my condition by various consultants and nurses and had time to carry out my own research and discuss my condition with my family. This meant that I made an informed decision about what I wanted to happen. Alternatives comment: I was lucky, my GP carried out the PSA test without question. This is in stark contrast to some experiences I have heard about. After my diagnosis my partner (also male) aged ***** at the time asked for a PSA test from the GP. The receptionist told him he couldn't have one as he had no symptoms. After explaining the situation and not taking no for an answer he was eventually given the test and thankfully was negative. I hear this and another similar stories often. There needs to be better education of medical staff and a change to the guidance so that if someone asks for a test they get one without having to fight for it. How many men take 'no' as an answer? How many of them have Prostate Cancer? Other comments: The world of Prostate Cancer is full of statistics – but behind every statistic are men, partners, families, friends and colleagues. Every single one of them is affected by a Prostate Cancer diagnosis. But more importantly and even worse is every single man, partner, family, friend and colleague that goes without a diagnosis, especially when if they had been tested their lives could have been saved.

P290	Affected Comment: This has affected me personally & quite a few family & friends. Evidence Comment: What happens to men who don't know they had a high genetic risk? When there are known high risk groups why ignore them. Discussion comment: Better awareness about prostate cancer. Recommendation comment: Screening should be recommended for all as it is until there is an improved one in its place. Why wait till men are symptomatic & diagnosis is too late. Alternatives comment: What are the alternatives???? Some time in the future might be too late.ther comments: All men should be aware of their risk & the opportunity to discuss this with a professional.

P291	Affected Comment: Yes, I was diagnosed with prostate cancer in *****, Gleason Score *****, grade *****. My diagnosis resulted from an ad-hoc screening offered by our local hospice *****. I had experienced no symptoms and didn't think I had any problems. It was therefore both a surprise and a shock. Due to my age (***** at diagnosis), surgery was not an option so treatment comprised Hormone Therapy starting immediately and Radiotherapy (***** sessions) starting ***** months after diagnosis. No alternative treatments were offered or discussed. Whilst I was advised to expect loss of libido as a side effect of the Hormone Therapy, the reality of this and the impact on my relationship with my wife was profoundly difficult for us both. In addition, significant 'brain fog' and a constant feeling of being sedated was very difficult to deal with. It appeared that the clinical professionals were entirely focused on dealing with the cancer itself with little consideration of the wider emotional consequences for both patient and partner. The fact that my aggressive (*****) cancer was found early was entirely due to random screening, giving me the best chance of effective treatment. Evidence Comment: I am not an expert in clinical evidence, but I would like to comment from a patient perspective. My cancer was only found at a treatable stage due entirely to a random screening event offered locally. It is important to arrive at a decision on screening that takes into account the devastating effects of prostate cancer which can never be reflected when just analysing data. Discussion comment: I was very surprised at the argument about a risk of overtreatment as surely any treatment would only be advised following biopsy or MRI scan, meaning no-one would ever be treated unnecessarily. Recommendation comment: I believe screening should be recommended, particularly for high risk groups, i.e. family history and particular ethnic groups. However, I myself don't fall within either of these categories and yet received a positive cancer diagnosis. Therefore, as with breast and cervical cancer screening for women, ALL men over a certain age (e.g. 50) should be screened. Alternatives comment: As prostate cancer is so often a symptom-less disease, national screening is really the only way to find the disease. Other comments: Whilst I would like to see the introduction of a national screening programme for prostate cancer, I also feel that funds should be invested in research which might lead to a more accurate test than the current PSA test. For now, however, this is the best and only test we have.

P292	Affected Comment: This condition has affected my family & friends. It affects me because my husband has ***** & is currently receiving treatment for prostate cancer. ***** is recovering from ***** & the other during ***** was found to have *****. ***** of my grandchildren may also be affected by this mutation. My husband would not have known he was at high risk of being diagnosed if *****had not been genetically tested when diagnosed with *****. Currently have friends being treated for prostate cancer who were unaware until symptomatic. Perhaps not affected me physically but definitely emotionally. Evidence Comment: Definitely. If a man doesn't know he has a gene mutation then he's not going to be regularly tested unless he has symptoms. Discussion comment: Personally I think it's a money saving conclusion which long term will not be cost effective. Recommendation comment: Screening should definitely be recommended. Men are often diagnosed in their fifties & sixties affecting their employment & employers. This is concerning if they have people dependent on them such as a young family. Alternatives comment: There could be better alternatives to the current screening programme but until those are in place why stop men using the current one. Other comments: Better awareness about prostate cancer for all ages.

P293	Affected Comment: Yes, I have advanced prostate cancer, stage *****. I was diagnosed in *****. My PSA when first tested was *****. Thanks to hormone therapy I have survived ***** years to date. Thanks to the Covid pandemic, I avoided surgery, chemotherapy and radiotherapy. Oncology didn't want to take the risk of admitting me to hospital and exposing me to the Covid virus. Because the metastatic spread was limited and we'd caught the disease relatively early, no major organs were affected and hormone therapy was sufficient to treat the spread into my bones, lymph nodes and soft tissue. Evidence Comment: Early detection, psa ***** , didn't work so well for my ***** who subsequently endured a difficult robotic operation, complicated by scar tissue from previous surgery. He did avoid metastatic spread though, due to early detection. Discussion comment: I thought that on balance, the conclusion was probably correct. There's no need to screen literally everybody routinely, but the NHS does still need to try to detect Prostate Cancer before it becomes too advanced. Improved public awareness of symptoms (*****) and GPs who are more alert to the disease and prepared to add a psa test to other routine blood tests (eg cholesterol) will help. Recommendation comment: Despite having Prostate Cancer myself, I'm against screening everybody due to extra costs and pressures that would impose on the NHS. Greater awareness and precautionary tests when men arrive at the GP for other reasons seems more sensible. Also, my ***** operation is a good example of the harm that can be caused. Regular monitoring may have been a better first option for him. I'm also very aware of the de-masculinising side-effects of hormone therapy. I feel like a pre-pubescent boy again, but I have to concede that my prostate cancer was still caught early enough to give me ***** extra years (to date) that I hadn't expected when given the original stage ***** diagnosis. Alternatives comment: Greater public awareness of ALL of the possible symptoms, not just the comical urinary related ones. Greater awareness of the PSA test being an alternative to the dreaded DRE test. Greater awareness of how treatable prostate cancer can be these days, if caught before it has spread to far. Other comments: Annual grants for charities like ***** who work hard to get men talking. Thanks to contacts that ***** founder (*****) had, we managed to get our logo on ***** for two races last year. It was great publicity and the team generously did that at no charge to us. We also went to ***** and were talking to ***** about Cancer in general. Imagine what might be possible if we had more funding and support.

P294	Affected Comment: I have had friends and family diagnosed late with prostate cancer because there is no national test screening Evidence Comment: No Discussion comment: I disagree with the policy not to have a national screening scheme Recommendation comment: Yes, there is insufficient early detection of the condition Alternatives comment: Early detection Other comments: No
P295	Affected Comment: Yes it has affected my brother, brother in law and several of my friends. Evidence Comment: No Discussion comment: Although the PSA test is not fool proof it is a better indicator than doing nothing, which seems to be the current approach. It is discriminatory to offer women routine and regular tests for breast and cervical cancers but nothing is offered to men. Recommendation comment:

	Yes screening should be routinely offered to men because of the high numbers of men who develop prostate and many cases could be identified much earlier so allowing much more effective treatment. Alternatives comment: By utilising MRI scans such as the LI-MRI scans or other which are being trialled. Other comments: Do something quickly before there are many more unnecessary deaths and serious issues.
P296	Affected Comment: No. Discussion comment: As an older man, I feel that there should be advice for older men who are asymptomatic on how often we should have a physical prostate exam by our GP. Most older men have urinary frequency, but if it becomes more frequent does that merit investigation? Recommendation comment: I understand that currently available investigations are not amenable to a general screening programme. But if particular groups are more susceptible, specific screening programmes may have merit. Other comments: It would help if we were informed of potential tests in development which might allow a future screening programme.

P297	Affected Comment: I have advanced prostate cancer. It was already advanced when it was found. Evidence Comment: From what I have read, the NSC failed to recognise that 'active surveillance' is widely used for older men, i.e. no actual treatment. The NSC failed to appreciate the early use of mpMRI scans. Discussion comment: The conclusion regarding over treatment is overstated. Recommendation comment: Screening should be recommended. It would enable a huge reduction in late diagnosis. Alternatives comment: I am not aware of any alternatives. I would advocate mass screening, although targeted screening could be sensible. Other comments: Scrap the TRANSFORM initiative. Disband the NSC.
P298	Affected Comment: Having eventually been diagnose with PC it out my life on hold and affected my family and marriage due to the unknown future. Although being diagnosed ***** years ago and a prostatectomy associated problems have always and still are a concern I have just undergone a endoscopic Urethral stricture proceedure due to a narrowing of the urether an after effectof the prostatectomy ***** yrs ago Unfortunately when your told PC it sets the whole family on edge Evidence Comment: the inclusion of family history and the possible effect on siblings. Discussion comment: I know from experience that PC has no warning signs in its early stages and by the time there are its often too late. I was lucky a doctor friend who subsequently passed away insisted I had the only test available a PSA which was gleason ***** and treated, it was found the cancer was on the point of breaking out so I was lucky. Diagnoses and treatment should not rely on LUCK Recommendation comment: Screening should definitly be recomended. Particulary where family history is involved and men in certain groups at high risk.

	My ***** who was over ***** had great difficulty in getting his GP to approve a PSA because he had no symptoms which should not be the case where his ***** and his ***** both have the disease. I realise in its totality, expensive, but surely this should be offset against the cost of treatment and patient/family concerns and worries, Not forgetting unnecessary strain on our already overloaded NHS where early diagnoses makes treatment so much easier Alternatives comment: I cant see any alternatives at this time, with research going on around the world there must be a simple blood test on the horizon which would be more accurate than the current PSA Other comments: Stop pontificating and finding so many negative and "why not" answers lets see something positive. If a fraction of the billions we use in trying to save the world were spent at home in this the highest silent killer of men it would be a start.
P299	Affected Comment: I have two ***** , one aged around ***** , the other aged ***** , the same age as myself. Both have been diagnosed with Prostate cancer. The former*****'s cancer has been found in time. Unfortunately, the latter ***** , the younger one who is the same age as myself, has been given a terminal diagnosis & been told they've got a "time limited lifespan" of around ***** years. He only got tested because he'd seen a news item about Prostate cancer on the BBC Breakfast programme one day. Considering he works ***** , it was only by luck that he saw that item on tv. So, with the above in mind, it must surely be beneficial to screen men from the age of 50? As otherwise, we're left feeling that we're potentially "sitting on a time bomb" that's waiting to go off! Recommendation comment: Yes, I do think that screening should be recommended, for the reasons I've already given. Men from the age of 50 are getting it, & not to screen from the age of 50 means we're left feeling like we're potentially "sitting on a time bomb" that's waiting to go off.

P300	Affected Comment: I have ***** stage **** prostate cancer which is not curable. I have had hormone, chemotherapy, radiotherapy and bone strengthening infusions. I am grateful for the treatment that has kept me alive but I now have to deal with the difficult continuing effects of the treatments including two collapsed vertebrae and nerve damage. What I can do now is rather limited indeed. The advice in the past was to see your G.P. if you had any symptoms. I had no symptoms but when I did have them it was too late. If invited I would have gone for a test. Evidence Comment: The continuing effects of the treatments on some patients do not appear to have been considered with as much concern as what treatment may do to men who may not need treatment. Discussion comment: The use of the PSA test and a MRI scan if considered necessary should be considered most important for all men over fifty years of age. Recommendation comment: Yes – why should men die when a test and scan may save their lives. The cost would be minimal as has been proven by the use of scans for ladies's health. Alternatives comment: The NHS and the government should encourage all men over fifty to request a PSA test at least every five years. Other comments: Please do not wait and let more men die unnecessarily.

P301	Affected Comment: I have recently been diagnosed with prostate cancer. Fortunately it was detected early and a number of treatment options are available. I had no symptoms but a chance decision to have a PSA test identified cancer risk which was confirmed following more advanced diagnostics. If it had not been for the PSA test likely the cancer would not have been detected until in a much more advanced condition. Accordingly my experience has been that a PSA test can provide indication of prostate cancer enabling earlier detection and treatment. Having a PSA testing programme would help to detect cancer earlier potentially saving lives. Evidence Comment: No comments Discussion comment: No comments Recommendation comment: I think screening should be recommended. Having a programme in place could enable earlier detection of cancer and improved treatment options. Early detection helped save my life. Alternatives comment: Creating public awareness of the need to check for prostate cancer through PSA testing or physical examination can only help. Continued investment in diagnostic tools to provide early cancer detection Other comments: In reality there is already an unstructured PSA screening programme in place as men can have a PSA test via their GP or privately. It is though, on an ad hoc basis driven by personal choice. Because it is not a formal programme there are men who miss the chance to be alerted to a potential problem. By having a structured and organised programme I believe that overall a more efficient and effective process can be put in place to support early detection of prostate cancer.

P302	Affected Comment: No Evidence Comment: Yes, I think they have missed evidence and their recommendation is biased for some other reason or motive. Discussion comment: They should work closely with Prostate Cancer UK charity and gather evidence and other points they missed out Recommendation comment: Screening should be made available as routine for men, especially for black and Asian men. Alternatives comment: It's not a case of finding alternatives here, men should be treated equally and fairly – we have breast, cervical screening and similarly we should do screening for prostate and other cancers early and that would save money for NHS in the longer run. Stop benefits given to people which all political parties are scared of or want to please thinking at vote bank, including stopping benefits for non citizens. Other comments: See above.

P303	Affected Comment: Yes, I am ***** generation Prostate Cancer patient. I know very little about my grandad as he died in ***** when family didn't really speak about illness etc... My dad's journey started when I was in my early ***** , he had all the main invasive treatments as well as medication and some very difficult time before he died of prostate cancer ***** ago. I am not ***** yrs old and was diagnosed on my ***** birthday, not the best birthday present for sure. Having PC effects the wider family and friends circle, most of them never raise the topic but I know they are worried. My biggest concern is I have passed this on through my children to my grandchildren, that worries me the most. Evidence Comment: No comments Discussion comment: No comments Recommendation comment: ***** I speak to many men and their partners (50% of the men don't engage, their partners do on their behalf). This statistic is part of the reason a national screening campaign and an awareness campaign are needed. Many men just won't ask for a PSA blood test until they have symptoms, this means they are likely to be further down the road than early diagnosis. GP's across the U.K. aren't united in their approach to PSA testing which is another major issue. I don't believe routine checks are the way forward but targeting the high risk groups like mine should be, along with a national education programme for raising Prostate Cancer and getting a PSA test. Alternatives comment: A national education programme on raising awareness of Prostate Cancer and when to get tested and who should get a test. The OSA is no good on it's own it's not accurate enough, an MRI should be included.

P304	Affected Comment: This condition has affected me directly. After feeling unwell in ***** my GP practice arranged for me to have a blood test based on the symptoms I was experiencing, which included a weight loss of ***** in ***** weeks. The blood test revealed a ***** and a high PSA (*****). A DRE suggested prostate cancer, Within ***** weeks I was admitted to hospital since my ***** had fallen to *****%. It was agreed that I required a ***** operation to overcome the immediate problem with my *****. At the same time as this operation a biopsy was conducted on my prostate. This biopsy confirmed I had prostate cancer. Due to the discussions with my GP and the consultants in the Urology department at the hospital, coupled with the extreme weight loss, this diagnosis did not come as a surprise. It was therefore not a shock to be advised that it was prostate cancer. Having told my siblings about the diagnosis, I found that ***** had experienced prostate problems although none had been diagnosed with cancer. This suggests there is an hereditary link Evidence Comment: I am not aware of any evidence being missed, although as a non-medical person, I am probably not best placed to comment on this Discussion comment: From my perspective it appears that the main driver in the conclusion is the cost of screening. Whilst this has to be a major factor since the NHS has finite resources, I personally believe that the cost of identifying cancer early will save money in the long term from having to treat and care for men once the cancer has advanced to a stage where it becomes untreatable. In my own case, the cancer was caught early enough that I have been able to undergo a course of radiotherapy and am continuing with hormone therapy. There have been some side effects resulting from the treatment, but these are manageable and are certainly much better than not having had the cancer discovered when it was not too late to be treated. Recommendation comment: I believe screening should be offered. In my own case, had I not felt unwell and gone to see my GP the cancer may have gone undetected until it was too late. Like a lot of people I speak to who have the condition, I had no symptoms of prostate cancer. Early intervention has been essential and due to the course of treatment my PSA has now fallen to *****. If there had been a screening programme in place my cancer may well have been detected earlier than it was, when I was aged *****. ***** In the absence of a national screening programme our group had arranged for a local testing event *****. Out of just short of ***** men being tested, approximately ***** will require further

	checks. We are confident that this will lead to people at risk getting the necessary help and treatment Alternatives comment: The only alternative to a national screening programme is for all men in the vulnerable age group who request a PSA test from their GP to be offered the test. There then needs to be a means of investigating further to ensure that the initial indication of possible prostate cancer does not lead to unnecessary treatment where none is required. At present it appears that some are refused a test simply because their GP will not offer it whilst others, as in my case, are tested and can then receive the necessary treatment Other comments: My only other comment would be that if a national screening programme is not to be offered then the criteria for who to include in any reduced programme needs to be widened. Currently the NSC recommendation does not include, for example, hereditary links. As mentioned above, Having told my siblings about my diagnosis I discovered that all *****have prostate health problems. I have one son who is now ***** years old and has been told he ahs to wait another 5 years before he can be tested. If he inherits what appears to be an hereditary link, it could mean that early detection is missed
P305	Affected Comment: Yes my Father and Uncle Evidence Comment: no Discussion comment: Too many men dying when preventable Recommendation comment: Of course it should

P306	Affected Comment: ***** of my friend have recently passed away due to Prostate cancer and I was told ***** of another friend who has been diagnosed with prostate cancer and is to undergo surgery on the *****. I am very surprised that the decision was taken not to screen all men over a certain age. I have had a yearly PSA test for the last ***** years after my closest friend was diagnosed with the disease. I also have annual bowel cancer tests. I am *****, play *****, *****, have a *****, and am involved in my ***** to help those ***** who run the *****. Discussion comment: Very Disappointed Recommendation comment: It gives men the knowledge as whether they may have the disease or not and the tests could be developed to have more certainty. The ladies in our country have tests to cover their main cancer why should men be classed as 2nd class citizens
P307	Affected Comment: I have been affected by problems with my prostate. Whilst it is not cancer, there is the potential for my current condition to develop into cancer. Evidence Comment: None Recommendation comment: My concern is that men are poorly served in the UK. Whilst women have regular screening for both breast and ovarian cancer, many men struggle to obtain a simple PSA test. I think therefore that the UK government should reconsider putting this new alternative in place. Alternatives comment: This is difficult to answer because I am not aware of other alternatives. Other comments: That the UK government reconsider it's position.

P308	Affected Comment: I was diagnosed with prostate cancer *****. Thanks to the intervention of an over 65 test offered to me by my local surgery, touch wood, all now seems to be normal. Without this test being offered, who knows what the outcome might have been. I also on a regular bases, checked the prostate cancer website to check the symptoms list. I had NONE AT ALL Recommendation comment: It should be available to everyone. Just imagine the uproar if the powers that be removed the national screening for breast cancer or cervical cancer. Let's hope that the idiots that are proposing this potentially killer idea, don't get prostate cancer themselves. Alternatives comment: With the amount of advertising on TV regarding this subject, it's hard to come up with any more that could be done, to make people aware of the potential pit falls of not having test. The best way to help people with this condition is to have a national screening programme and leave it at that. What costs more (let's face it, it's all down to money, so the government can give it away to other countries) diagnosing it at an early stage and treating it, or having to have long term care at extra cost, knowing the regretful outcome. Let the government decide this. Just make sure you can live (unlike the person who's just died from this condition) with your decision. Other comments: In act a national screening programme now. Prove to us that you do care

P309	Affected Comment: My husband has ***** prostate cancer that has now spread to his *****. If his condition had been diagnosed earlier he would have had more chance of living a long life. We understand that the PSA test is not the most accurate test to determine prostate cancer however if used as a first defense, with follow up tests it could save many lives. Women have several screening programs for cancer and wide media coverage of the disease and we think it is discriminatory not to give men equal opportunity to be informed and screened on a regular basis. Discussion comment: As the largest killer of men, more needs to be done to prevent and educate Recommendation comment: Screening is vital. As I have said above it is a good first stage indicator and should at least be offered every 5 years from the age of 40. Alternatives comment: Education and media coverage. Other comments: Always preventing or catching major health problems earlier will cost the NHS less in the long run.
P310	Affected Comment: My father was first diagnosed with prostate cancer in his ***** and successfully underwent radiotherapy plus hormone treatment that resulted in him living until he was *****. Unfortunately he died In ***** of advanced prostate cancer however it was his regular PSA testing that detected it again that allowed for further hormone treatment and an additional ***** months of precious time with his family. Discussion comment: Based on my experience of helping him with his condition, visiting the hospital etc and listening to various Consultants, almost all of them clearly felt that regular PSA tests were of value as the encouraged me to get checked regularly. I do this but pay for it as my NHS GP refused to do it more than once, at the point I initially asked to be screened annually. Recommendation comment: Alone, it might not work, but in conjunction with an annual discussion with a GP and possibly a physical it will help.

P311	Affected Comment: I have family members who have been diagnosed with this condition. Evidence Comment: None to add. Discussion comment: The discussion seems to indicate that screening will cause concern or confusion. The same would be true of any screening. Technically the success rates seem much better now than some years ago. Recommendation comment: Screening should be recommended. It will save lives and impact. Alternatives comment: If it's not a matter of course, then GPs could offer advice and the option regardless. Other comments: It seems quite shameful that men are forced to ask for screening.
P312	Affected Comment: Yes, I ended up having ***** sessions of radiotherapy Evidence Comment: I fail to understand why the UK government have not already set in place a screening program for the UK's most common cancer. A simple blood test be it PSA or PSE. Discussion comment: See above Recommendation comment: Screening should definitely be recommended. Alternatives comment: I have seen no evidence of alternatives to screening programs. From evidence I have seen from others it would appear that the NHS guidelines given to GPs are sadly lacking, resulting in them discouraging patients from having a simple PSA test even though the NHS constitution says if you are over 50 you are entitled to a PSA test even if you do not have any symptoms. Other comments: This cancer will affect more patients than any other cancer so you need to extract the digit and do the right thing.

P313	Affected Comment: I had a PSA test which came back as *****. GP said NHS guidelines state anything under 5 is considered normal. I had a private biopsy and diagnosed with advanced Prostate Cancer I was subsequently treated and had a prostatectomy My consultant told me if I had left it as advised by GP it would have spread very quickly around my body Discussion comment: Not screening people will cause deaths Recommendation comment: My experience proves that screening saves lives Alternatives comment: mpMRI scans being far more available
P314	Affected Comment: As someone who is over 65, I am in the group at most risk and need screening. Discussion comment: As someone who is over 65, I am in the group at most risk and need screening. Recommendation comment: Screening should be recommended.

P315	Affected Comment: I know of several friends that have prostate cancer – ***** – all are undergoing treatment and did not initially have symptoms. Evidence Comment: Prostate cancer has increased in men quite significantly to be dismissed with targeted screening only. We now need a national screening programme with clear guidelines based on test results – see my comments in next box regarding the NHS app and test results. Discussion comment: Prostate cancer has increased dramatically. Targeted/select few being tested is now not enough. NHS are very good in putting men off getting tested and then when they are tested or force the issue it is too late for many – just look at Sir Chris Hoy as one prime example. There should be testing for ANYONE at risk with clear guidelines based on test results on the frequency of testing as there is too much ambiguity as to when to have a retest. Should it be yearly – yes and also based on your result. The NHS test results on the app shows a green band 0-4 yet you can be in the green band and require a test if its over 2 – how can that be. Surely it should be a green band of 0-1.99 only. Then if you are within this 0-1.99 how frequent should you be tested – every 6 months or yearly or every two years – although my thoughts are two years is too long and will cost lives. Recommendation comment: National screening should definitely be recommended – now not in 6 months time or later. Prostate cancer is more prevalent now in society that's why. Many are being missed as not showing any symptoms and by then it is too late. Caught early treatment is more successful and that is fact but as no symptoms is common place – National screening can catch it early and save lives. Alternatives comment: Until alternatives have been found you will still need a national screening programme that is well thought out and regularly administered to all men. Other comments: See all previous boxes.

P316	Affected Comment: Yes. Father died due to late diagnosis. I am at risk due to Enlarged Prostate Evidence Comment: Yes. Even if PSA screening is not fully effective its better than nothing and men finding out they have late cancer. Regular (not one off) PSA tests give a better indication of increased risks. The cost of PSA tests and overdiagnosis is surly cheaper than treating terminal cancer and the loss to the nation of excessive and avoidable deaths Discussion comment: They are wrong in the stick to purely medical testing outcomes and do not see the wider picture of avoidable deaths Recommendation comment: annual PSA test for every man over 30 should be started without delay Alternatives comment: Currently no alternatives to screening, but may be research will help in the future to enable more accurate diagnosis. NHS and GPs should make men more aware of symptoms and risks Other comments: Start PSA screening in 2026

P317	Affected Comment: I am ***** years old and have been testes for PSA for eight years. My doctor carried out thorough blood tests for a number of years and my PSA results eventually reached a level where they were of concern. I was referred to the local hospital for tests and found to have ***** Prostate Cancer. After a cystoscopy and biopsy I was advised that the cancer was spreading into my urethra. I was recommended to have radiotherapy which was carried out ***** At my last PSA test in ***** the result was ***** and the radiation treatment is deemed to have been successful. I will continue to be monitored for PSA for the rest of my life. If it was not for the persistence of my GP's and their insistence for testing I would not be in the good position I am today. Please reconsider the proposal to limit screening. Evidence Comment: See above Discussion comment: See above Recommendation comment: If it was not for the persistence of my GP's and their insistence for testing I would not be in the good position I am today. Please reconsider the proposal to limit screening. Alternatives comment: No comment Other comments: There is still a great deal of ignorance regarding cancer and particularly Prostate Cancer. A targeted programme of publicity would greatly raise awareness of this killer of men.

P318	Affected Comment: I have a family history of Prostate Cancer, with ***** brothers being diagnosed and successfully treated. I have been diagnosed with Prostate Cancer, but was treated with hormone treatment and Radiotherapy. Luckily it was caught early. Evidence Comment: I understand their logic, but it excludes many high risk men. Discussion comment: I think it should be extended to men with a family history of the disease. Recommendation comment: I think it should but only to high risks (Ethnic, Family History, Genetics) Alternatives comment: More education and more accurate blood tests Other comments: More awareness and education.
P319	Affected Comment: I am a prostate cancer survivor and I had family history. Father died aged ***** with advanced PCa and Mother had survived ***** cancer after surgery and radiotherapy. ***** has now been diagnosed and is on AS. I had surgery in ***** followed by salvage radiotherapy and am a happy survivor aged *****. I was asymptomatic at diagnosis. My wife, *****, encouraged me to have annual PSA tests from age 50 and my GP was sufficiently enlightened to accede to this. Over the next ***** years my PSA was static within acceptable levels but at age ***** it elevated to *****. I was referred to secondary care, had further tests leading to a transrectal biopsy showing *****. I opted for a radical prostatectomy (*****) and subsequent histology showed a positive margin. ***** years later as PSA was rising I was referred for salvage radiotherapy (*****) and today I am a survivor and a missionary encouraging men to take care of their health. I am a ***** member of our local support group. Evidence Comment: I am concerned that too much emphasis has been placed on historic evidence without cognisance of current circumstances. Discussion comment: I am concerned that in recent years men have taken up PSA testing opportunities provided by organisations such as the ***** who have provided testing for hundreds of thousands of men. Many employers are actively providing testing for their staff including the Police, Fire Service and organisations employing large numbers of men. Most are using the services provided by

those such as ***** – why do we need to pay for such a service when there are NHS programmes for bowel, breast and other cancers.

Men are now prepared to take responsibility for their own health, particularly if they have been denied testing by GPs.

This testing opportunity should be provided by the NHS without compelling men to seek alternatives.

Recommendation comment:

Prostate cancer is the biggest cancer in men in the UK with over 60,000 diagnoses annually, leading to over 12,000 deaths. It follows that thousands of men are living with PCa and its consequences, whether or not they have received treatment, probably because they have not been diagnosed at an early, treatable stage.

Screening purpose is not solely to prevent premature death but to encourage men to receive an early diagnosis at a treatable stage. Too many men are diagnosed late when PCa is at an advanced stage.

I passionately believe in screening, it saved my life.

Alternatives comment:

The PSA test is NOT a diagnostic tool, it merely flags the need for further testing/investigation. There needs to be a clear understanding that the PSA check merely provides patients/clinicians with the need for further investigation. The DRE is being dropped widely as it is not accurate and can only examine one side of the prostate. The subsequent MRI scan starts the diagnosis process.

The former transrectal biopsy could lead to serious infection but nowadays most biopsies are trans perineal which is much safer. There is now much reduced potential harm.

Other comments:

In our support group most members were asymptomatic but had been diagnosed through an employee health programme, through their own initiative or as a result of “word of mouth” encouragement from friends and family.

I am amazed at the number of patients who are refused PSA testing through their GP; frequently being told to go away and only return when they experience symptoms. I believe it is imperative for GPs to be educated so they can respond more positively to patient requests.

I would be happier if GPs took an active role in inviting men with ethnicity or family history to be tested regularly from age 45.

P320	Affected Comment: I had no symptoms and prostate cancer did not affect my life at all. More than 2 years after the prostatectomy the after effects are mild urinary incontinence and erectile dysfunction. Evidence Comment: Did the committee have evidence of the number of men who were diagnosed with prostate cancer without symptoms, Discussion comment: Choosing a small number of men with BRCA1 or BRCA2 to be screened is very short-sighted, Recommendation comment: Regular screening of men by a blood test (PSA) will indicate, over time, changes in the prostate. Alternatives comment: At the moment, PSA testing is relatively cheap and simple. MRI scanning is developing and hopefully will provide a more reliable test. Other comments: Research is needed to show if diet affects the incidence of prostate cancer. (Japanese men have a very low incidence)
P321	Affected Comment: While Prostate Cancer hasn't directly affected me, I have been diagnosed with *****, so am very aware of potential risks of the disease. Evidence Comment: No comment. Discussion comment: I am upset that the use of regular screening for prostate cancer has not been recommended. Recommendation comment: I think it screening should be recommended. I demanded a PSA test on *****, which was directly responsible for the diagnosis, but by then I was already having symptoms. While it's not showing cancer yet (and hopefully won't), I would still have been prepared to get regular screening as I also have *****, and initially put symptoms down to that. Regular screening may have made me aware much earlier. Alternatives comment: Better education and talking about in to all men when they go to the GP, for any other condition. Make them aware the test is there, and present the option to have it, false positives explained. Other comments:

	Make men as aware of the test and to offer it, the same as women have been made aware of, and are offered, breast and smear tests.
P322	Affected Comment: I have a really good friend who at the age of 59 has now been diagnosed with stage 4 prostate cancer. Screening at 50 would have picked this up
P323	Affected Comment: Not affected by prostate cancer Discussion comment: Very few men know their likely or actual BRCA2 status, so unless men are screened for BRCA2 status routinely, the recommendation will mean that men are not offered any ability however flawed to find out if they might have prostate cancer. Any positive PSA test would in any case be supplemented with MRI to investigate further and recommend possible treatments. My recent experience with my own GP is that requests for a PSA tests are now refused. I feel that the health interests of older men are being ignored. Recommendation comment: However flawed, PSA testing is the only test available, and should be available on request. Most elderly men are likely to suffer from BPH and a test enables them to differentiate these symptoms from possible prostate cancer.

P324	Affected Comment: My husband was diagnosed with ***** prostate cancer in ***** which had spread to a *****. He had had no symptoms; the cancer was found because his GP surgery invited him for a 70+ general health check and he asked for a PSA test to be done at the same time. The GP – fortunately for my husband – agreed to this, but under the U.K. NSC’s current proposals it seems unlikely ***** would do so now in the same circumstances. There was no identified familial risk of prostate cancer. My husband’s PSA was ***** My husband’s cancer had a Gleason *****. He is being treated with both radiotherapy (gruelling) and anti-testosterone injections over *****. Had he not requested the PSA test last year, by the time he became symptomatic he may well have been at an advanced stage and his prognosis poor. He had been an incredibly fit man, ***** , although his regime is less punishing now. I feel the U.K. NSC recommendations over-state the risks from false positive diagnoses (through the PSA test) and under-state the risks of missed diagnoses to an unacceptable degree. Their rigid approach is not the one taken by other advanced healthcare systems and I don’t think the government should accept their conclusions. Evidence Comment: I don’t know what national and international datasets exist re asymptomatic patients like my husband who are later found to have prostate cancer that is not slow-growing and definitely needing treatment. But if this exists and was not factored in, it needed to be. Discussion comment: As previously stated, it under-states the risks of missed diagnoses of a truly devastating disease v. over-diagnosis. Where we live (*****) our local NHS Trust *****. If all NHS providers were equally competent, the risks from needless and harmful over-treatment would at least be minimised. Recommendation comment: I think there should be controlled screening trials using PSA and MRI (which I’m guessing may not be currently available in sufficient capacity within the U.K.) based on risk-stratification models such as those developed for the European PRAISE-U project. Alternatives comment: Learn from international best practice: where evidence remains equivocal, develop clinical trials urgently to test risk-stratification models for detecting prostate cancer. Also, despite high-profile cases of celebrities with prostate cancer, many men we know personally remain incredibly ignorant about prostate cancer and the potential benefits/risks of PSA tests. There needs to be targeted education to support men with this in the same way there was for breast cancer when screening was introduced in the late 1980s. Other comments: As above – education for all men as to the issues around diagnosis. Really listen to feedback from Prostate Cancer U.K. and Tackle Prostate Cancer and take on board what they say.

P325	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: It should be recommended
P326	Affected Comment: Prostrate problems experienced by both my brother and father. Recommendation comment: Sreeening should be recommended. It best supports early treatment where necessary. And risks of over treatment can be avoided by good information provision. The screening information in itself also increases awareness and prompts preventative actions. Alternatives comment: There is no alternative to level of diagnostic information provided through screening. Other awareness and information activities are important and goo, but ancillary.
P327	Affected Comment: Yes I had prostate cancer and I am now in remission since *****. My cancer was advanced with only a minor symptom and I am lucky to be alive as it could have spread imminently.The Gp would only refer because I had a symptom.This is not good enough.I am ***** yrs with a wife, ***** daughters and ***** grandchildren and I was lucky,many many men are not. Recommendation comment: It should be.The positive diagnosis rate on testing is better than mammagrams. Alternatives comment: Develop saliva testing.
P328	Affected Comment: Not been affected but, could be. Recommendation comment: Should be recommended

P329	Affected Comment: I was diagnosed with prostate cancer in ***** and had a prostatectomy (*****) ***** weeks after diagnosis! I now consider myself cancer free and have a PSA below the level of detection. I am now in good health at the age of *****, the only notable collateral damage I have is urethral scar tissue which I manage with weekly intermittent self catheterization. Discussion comment: I feel strongly that a national screening programme for prostate cancer is essential. If this were a women's issue we would have had screening long ago, in my opinion! Recommendation comment: We must have national screening. Prostate cancer is now the most common cancer. Despite this, knowledge and awareness amongst men in particular is alarmingly poor. Furthermore, unlike women, who largely are proactive in health matters, men are in denial. Over and again I hear anecdotes of men with a father or brother who've had prostate cancer but who won't be go for a checkup. It won't affect them, of course not! Only through screening can men be jolted out of their apathy and the countless, senseless deaths be dramatically reduced. Other comments: It is almost universally accepted that blood PSA levels are indicative rather than diagnostic. A single reading is of little value. A second test, say, six months later by comparison gives more information, especially if the score has risen. My first PSA test was in*****. It was *****. I had an MRI and a perineal biopsy and was advised to return if my PSA went over 7, which it did the following year. The tests were repeated, along with a PET scan and ultrasound and cancer was confirmed and operated on. Looking back, I'm not sure the tests in ***** were appropriate, but the repeated PSA blood test is the key. The diagnostic tests are not fun, especially the biopsy. I do think the case of false negatives and positives is overstated. Furthermore, it gives fuel to those GPs who still prefer DRE to PSA. (Really!). Luckily, my doctors are more enlightened. I have been very lucky. It pains me enormously to see so many men suffering and dying needlessly because of this awful, but largely curable, condition.

P330	Affected Comment: ***** friends (not blood relations) recently have gone through a stressful few months after self-reporting early indicators and awaiting many weeks for clearance. Availability of an early screening test would encourage proactive testing and avoidance of delay, worsening of the potential condition and more complex treatments. As a baby boomer, *****, I get a test every two years. No family history, but contacts from University ***** and work ***** demonstrate a continuing threat to many able-bodied men. I support the local ***** team, raising awareness and funding outreach. Evidence Comment: Keep exploring options for testing and treatment. This is not a simple cancer, it affects different men in different ways – heritage, background, DNA, – it is worldwide, like breast cancer.it is hormonal. Discussion comment: No comment Recommendation comment: Well researched, evidence based screening should be trialled and tested and deployed as soon as possible. Disabled men (and women) are an expense that is avoidable, if the condition is identified and dealt with early enough. Alternatives comment: These alternatives need to be researched and assessed for relevance but don't throw away the findings, new treatments may be developed that exploit these alternatives to develop cheaper, more effective treatments in future. Other comments: No. This is a complex subject that needs resolution.

P331	Affected Comment: In *****, aged *****, I went to my GP with mild discomfort. I was concerned because my ***** had died of aggressive Prostate cancer, but my GP assured me that it 'definitely won't be prostate cancer' because I was 'too young'. Thankfully, he proceeded with tests and aggressive Prostate cancer was diagnosed which was luckily still only at *****. I was offered an urgent radical prostatectomy, but after excellent counselling from a wonderful Macmillan nurse I was treated successfully with *****, with no impact on my continence and minimal impact on erectile function. I have been cancer free ever since. As a counter to this, a very good friend of mine whose father had died of prostate cancer went to his GP with mild symptoms, but was actively discouraged from pursuing investigations, being warned of the consequences of so-called 'over diagnosis'. My friend ***** symptoms persisted, and by the time the GP actioned investigations, it was too late and he had ***** Prostate cancer that had metastasised to his bones. After multiple rounds of extremely challenging chemotherapy, my friend died *****. As a ***** I went on to document my experiences *****. I was utterly dismayed to see the NSC recommendation against a national screening programme. I have also informally 'buddied' numerous other men facing the same choices I faced. Evidence Comment: I question the evidence, the language used, and the way it is presented in several significant regards. Firstly there is an over emphasis on the shortcomings of the PSA test. It is repeatedly asserted that PSA is not an accurate enough test for cancer. This is because it isn't, nor has ever claimed to be a test for cancer at all. What a PSA test does well is simply indicate whether the prostate is in trouble. It is then for further investigations to establish whether or not this is because of cancer. And then to assess those results properly to decide whether further intervention is required. I am dismayed to see this false conflation perpetuated on the NSC Gov.UK webpage. It's a misleading, straw man. The language needs to be changed as a matter of urgency as it distorts the argument. PSA is a useful indicator for further investigations but no informed clinician would consider it a 'test for cancer' therefore to predicate a decision regarding screening on its inadequacies in that regard is a dangerous logical fallacy. Secondly, there is repeated use of the phrase 'overdiagnosis'. This again is an invidious use of a word that leads to confirmation bias when evaluating the arguments. There is no such thing as 'overdiagnosis'. Prostate tumours are either there or they aren't. The issue – which can lead to unnecessary interventions – is what the clinicians do next, and how they advise the patient. I received excellent counselling which enabled me to make the best possible decision, but again and again I meet men who have had little to no guidance in this area. The problem is not 'overdiagnosis' if you insist on that word, but what follows on from diagnosis, and the potential for poor decisions and choices subsequently. The issue is to improve those decisions which you can't do without a diagnosis. i.e. you can't make the right decision if there is no diagnosis at all. To remove the potential for diagnosis makes no logical or clinical sense whatsoever. Thirdly, there's little to no mention of inconsistency of treatment pathways available across the country. I was lucky because I live near ***** but I often speak to men who aren't offered the same choices I was, the default being radical prostatectomy, which in turn is not consistent because some places do nerve sparing better than others. The degree of incontinence and

erectile dysfunction are also determined by variations in surgical, available kit etc. Don't blame testing for failures in provision.

Lastly, there is no mention whatsoever of poor GP training (my GP had never even heard of the treatment I had) nor of the surgical machismo encountered at the consultant level which can put pressure on a patient to go for a more invasive procedure than they need. In essence, I don't believe the documents I read reflected the lived experience of many men facing choices when given a prostate cancer diagnosis.

Discussion comment:

I also question the statistical modelling which I see as superficial or reductive. It is suggested, for example (in the final infographic) that if 1000 men aged 50-60 are tested, 28 cancers would be diagnosed, but 20 would be 'overdiagnosed' (I really object to that term), 2 lives would be saved, but 12 men would be 'over-treated'. This is modelling at its most crude and obstructive because it assumes no change in behaviour once a national screening programme was introduced. A national screening programme would (one would sincerely hope) be accompanied by vastly improved post diagnosis support services helping men to make better decisions and avoid unnecessary interventions. It also assumes a consistency in clinical care that simply doesn't exist in the real world. With the right investment of time, thought and money this statistical modelling would be rendered almost entirely redundant. Accepting it, is an exercise in classic confirmation bias.

What this modelling also suggests is that the NSC have decided that allowing two in a thousand men to either die, or not have their cancers picked up until they have spread (requiring more expensive interventions) is somehow an 'acceptable' or 'preferable' alternative to the twelve men being 'over-treated'. This demonstrates a failure of clinical logic nor is humane on the most basic of moral levels. It's not a case of either or. I would expect the NHS to save all the lives it can, but improve the system to avoid unnecessary interventions and side effects. Pitting one against the other is again invidious and frankly something the committee should be ashamed of.

I am also incredibly disturbed by the insistence on these terms such as 'overdiagnosis' because when placed in the public arena they act to stigmatise the whole idea of screening or PSA testing of any form. It's hard enough to get men to look after their health – and even harder to get black men (more prone to the disease and more prone to aggressive forms of it) to get themselves checked. The report seems to be arguing that it's easier to live in ignorance. This is an unsustainable argument and I don't believe that the committee have quite understood the negative power of their words or their own confirmation bias, or how dislocated they are from the realities of men's health.

There is a view that there is a level of 'over treatment' of women's breast cancer, but I can't see the NSC recommending that the NHS stop doing mammograms.

Recommendation comment:

I absolutely believe in a nationwide screening programme for men over fifty – because as either so many other screening programmes (bowel cancer, breast cancer, aortic aneurism, lung cancer etc), by making it universal there are a minimum of hoops for men to go through in order to get the potentially life saving treatments which ought to be available to them. All of those screening programmes have been accompanied by improved information and education to help and guide people through whatever diagnoses may come. The same could and should be offered for prostate cancer and it's mystifying that this report seems to assume that screening would happen without those improvements and be used simply as a blunt tool.

It is undoubtedly true that, at the moment, too many men are embarking on unnecessary treatment pathways with avoidable long term side effects – but the NHS should be solving THAT problem, not blaming diagnosis (and calling it ‘overdiagnosis’), not sticking its fingers in its ears arguing that it’s just better if men are left in ignorance.

So, I suggest three flanks to solving the problem of unnecessary interventions to GO ALONGSIDE a national screening programme – which are perfectly possible to address:

1) Ensure a far higher standard of patient counselling as to appropriate treatment pathways. Invest more in Macmillan Nurses (who can advise independently of in house NHS pressures); revise the treatment literature which when I was diagnosed was inconsistent and impenetrable at time; invest in a ‘buddy’ system, because men quite understandably would like to talk to other men about something so personal that could affect their sexual and urinary function; and invest in support groups rather than just leaving them to chance and charity.

2) Improve and set far better standards for GPs and dedicated prostate clinicians with regard to this variety of cancer. The landscape of Prostate care changes by the day, and busy GPs struggle to keep up, and consequently can make poor decisions (as with my friend *****) and frankly don’t have a clue about what their patients are encountering. This could be improved by better in service training. Similarly the hospital clinicians need to take a long hard look in the mirror and think about how their behaviour – especially surgical arrogance and machismo – could be adversely affecting patient outcomes.

3) Ensure that up-to-date treatments are more widely available across the country as a whole removing the post-code lottery of what individual patients may be offered. This would require major investment and perhaps increased support for patients having to travel greater distances to access up to date treatment pathways.

Alternatives comment:

I don’t believe there is an adequate alternative to a national screening programme for Prostate Cancer, for the reasons I have outlined in my previous answer. The second it ceases to be a universal offer it creates hoops for men to jump through and as I think is widely recognised, it is more likely to be white, middle-class, university educated men who take the time and trouble to watch out for this aspect of their health.

I would also add that the idea that ‘you’re too young for prostate cancer’ in your fifties is not only untrue but also a sticky one (as demonstrated by my own GP), partly because of reports like this! Consequently many men I know don’t even think about their prostates until their late fifties, but as I understand it, the younger you get cancer the more aggressive it’s likely to be. Men in their fifties are still working, perhaps still bringing up kids, and they’re just not thinking about this condition as a possibility – so by making it a national screening programme every man in his fifties will at least get that ‘nudge’ to think about checking the potentially dodgy walnut nestling beneath his bladder.

Other comments:

I would really like the committee to think a lot harder about their language and about the real world as I have illustrated in my previous replies. Far from umming and ahing about prostate screening, it would be far more preferable for the NHS to start talking positively about how it should be best employed. There are large cohorts of men – younger men, men of Afro-Caribbean heritage – who need all the encouragement and nudges that the health service can offer. Try not to think about this purely in terms of statistical modelling – but refocus on the lived experience of men and prostate patients. This also means that health practitioners need to look

at the role THEY are playing in some of the more negative outcomes the committee claims to be concerned about. There is considerable room for improvement. As it stands, the report comes over an exercise not only in confirmation bias, but victim blaming.

And remember at all times: There is no 'acceptable' mortality rate for not having a national screening programme backed up by fully informed counselling to reduce unnecessary and potentially harmful interventions.

To suggest otherwise, I say without apology, is tantamount to state sanctioned criminal neglect, a neglect leading to thousands of men having to deal with late stage prostate cancer and hundreds if not thousands of unnecessary deaths every year.

P332	Affected Comment: Myself and friends Discussion comment: The conclusion and recommendation assume that a blood test resulting in a raised PSA reading is automatically followed by treatment, such as radiotherapy, hormone treatment or a surgery pathway. This is just not the case. It is likely that the GP considering a PSA test will first perform a digital rectal examination (DRE) to assess physical evidence. One raised PSA result is most likely to be followed by a further PSA test after an interval to see how the results vary. Should this also give a raised reading, referral to a consultant will probably follow. In my case, the consultant performed another DRE and confirmed my GP's suspicions. An MRI scan is likely to be carried out as part of this process, which should give a good idea of whether a tumour is present. As my tumour was very small I was placed on Active Surveillance, with 6-monthly PSA tests and regular (annual?) MRI scans. Apart from occasional biopsies (uncomfortable, but worthwhile in my view) I had no intervention for about ***** years, while the team kept an eye on my tumour. When my 6-monthly PSA readings started increasing more rapidly, it was decided to intervene. The consultant proposed prostate removal and was keen to do this while I was in good health and still in my *****. In the event, I had radiotherapy, which ended over ***** years ago and left me with no ill-effects. I believe the risk of over-diagnosis is very small. The real risk, in my view, is leaving men until symptoms develop, by which time it is likely to be too late to eradicate (as in the case of Sir Chris Hoy). I had no symptoms and am very pleased that my GP was on the ball. Recommendation comment: Yes, for the following reasons: * By the time symptoms develop it is likely to be too late to eradicate the cancer. * Men with a close family history of prostate, breast or ovarian cancers are at considerably higher risk of developing prostate cancer. * Men of African-Caribbean heritage have around twice the average risk of prostate cancer. * Men with discomfort passing water, or getting up 2+ times a night to do so, would also benefit from assessment. Alternatives comment: How will they know they have the condition (prostate cancer) if they are not screened? At present, PSA testing, backed up by an MRI scan, is the best method we have.

P333	Affected Comment: I was first tested for PSA in *****, when I was living in *****. I did not have any symptoms and went to the doctor on an unrelated matter. Due to my age at the time, *****, he asked if I had ever had a digital rectal exam and a PSA test, which I hadn't. My PSA was slightly abnormal, and continued to rise over time, and I was monitored and tested for ***** years before being sent for an MRI scan and biopsy. The results were inconclusive, and I continued to have annual MRIs and biopsies until ***** when I was formally diagnosed with prostate cancer. In *****, it was recommended to have treatment, and I elected to have a radical prostatectomy in *****. Evidence Comment: I would like to know whether the UK NSC studied the impact of screening programmes in other countries. This would surely provide material evidence on whether a national screening programme was cost-effective. Discussion comment: I find it sad that the review did not recommend a national screening programme. My cancer was detected as a result of being in *****, which has a screening programme. If I had been living in the UK at the time, I would not have been monitored, and my cancer would likely have developed to an incurable stage, as I have never had any symptoms. I think the recommendation is shortsighted, as I have a feeling the cost of a screening programme is small compared to the cost of treating people for years, when a screening programme gives people like me a chance at curative treatment. The committee has recommended only screening for people identified with the high-risk genetic markers, which is only a fraction of the number of men who get diagnosed with prostate cancer every year, so it's as good as not having any screening programme for the majority. I fear this decision will only further discourage GPs from agreeing to PSA tests for men with no symptoms or family history. I think the dangers of overtreatment is a separate issue, rather than justifying why to reject a national screening programme. Better education, guidance, and safeguards could help men make the right treatment decisions instead of penalising all men by denying them the chance to make an informed decision about treatment. Recommendation comment: I think it should be recommended because it gives all men a chance to catch prostate cancer early and have the best possible outcome. I find it incredible that nobody questions why there is a breast cancer screening programme, because of the risk of over-treating women for the disease. I understand testing for prostate cancer is problematic, and many men may never need treatment, but by not having a screening programme, you are not giving men a choice to make their own treatment decisions. Alternatives comment: Better education. I have spoken to many people who believe you should only see a GP if you have symptoms linked to prostate cancer, which is a common myth.

	I believe the NHS should have a periodic wellness check, say every five years, for men over the age of 40 and include a PSA test.
P334	Affected Comment: Bringing in testing for all is vital if we are to save lives
P335	Recommendation comment: At age ***** I wouldn't have known I had prostate cancer unless my GP offered a PSA test. My cancer was caught early. My good fortune. Other comments: Additional medical services asap following radiotherapy would be beneficial. At the moment there's no regard to providing rehabilitation.

P336	Affected Comment: I lost my brother to a late diagnosed Stage ***** Prostate cancer that had spread to his bones. He died within ***** years of diagnosis despite chemo and hormone treatment. He died aged ***** , leaving a wife and ***** who he never saw go to university, learn to drive or get married. As a result, I got tested (my familial link was recognised and accepted by my NHS GP) and my levels were elevated, and increasing and that triggered “harmful” testing and treatment as your studies call it, I had the digital exam, the MRI, the template biopsy, RARP and then later needed ***** RadioTherapy doses. I also know a number of people at work that have gone through a similar experience. Evidence Comment: None of my experiences with cancer were pleasant, although I must say that the main positive was that I met some amazing people, and the NHS staff that have extended my life were all fantastic. I have experienced some of the “harmful” side effects mentioned in the studies. However, the studies are biased in stating these things as harmful. They are necessary trade offs that have to be accepted in order to beat the cancer into submission. Every patient has choice over their treatment – the risks are explained. The “harm” is worth it for the majority of patients and this enquiry seems to be over stating the harm element of treatment. There is also a lot of emphasis on cost. So overall, what is missing is the impact from a human perspective. Hopefully my comments can help address this. Discussion comment: I think the review emphasises a perception of harm, concentrates on cost and ignores the human aspect. It aims to take away the right of choice from cancer sufferers. We should be able to choose whether or not to accept the risk of harm during the treatment process, and in order to do that, men need to know they have prostate cancer in the first place. As it is largely a cancer which only has symptoms when it is too advanced to cure, screening is vital to save men’s lives. Recommendation comment: Screening must be recommended. If my brother had been screened then he might have been saved by the same early diagnosis I got (that his death, gave me). Women get breast and cervical cancer screening, men should be able to get the same for PCa – if not this is blatant sexism. Surely the same arguments against women’s screening apply, yet they have got it – why shouldn’t men have that too? Alternatives comment: The main alternative to screening, this enquiry seems to be suggesting is to save money by sticking their heads in the sand and avoiding the diagnosis of men and effectively giving them early death sentences. It seems obvious that money is the main driver. But if more men were diagnosed EARLY, the treatment will be simpler, shorter, easier and less expensive thus saving money. Also, by concentrating on diagnosing younger men earlier, more working age people would be saved thus protecting tax revenue and allowing more pension accrual. Other comments: The human side of this must be considered. Please think about the family members of those with this terrible disease – anyone who has seen someone die from it knows that giving men the

	option of detecting PCa EARLY enough to allow them to DECIDE if radical treatment is for them and their families or not is vital. To use money and a bit of risk, to argue against the provision of Prostate Cancer screening (in any form) is blatantly immoral. PLEASE PLEASE DON'T LET MY BROTHER'S DEATH AND MY SURVIVAL BE INVEIGN.
P337	I would like the organisation to be involved in prostate cancer screening conversations.

P338	Affected Comment: I was diagnosed with Stage ***** Incurable Prostate Cancer which had spread to my *****. My treatment since then has involved ***** days of radiotherapy and then ***** years of Androgen Deprivation Therapy (*****). I have had the common side effects: hot flushes, fatigue, complete loss of sexual function, weight gain, depression and anxiety, and severe muscle loss and joint pain. The radiation damage to my ***** has made me periodically *****. Living with Incurable PCa, because of the brutal treatment side effects, is life changing. I had a PSA test every year from the age of *****. I didn't between ***** because of COVID and caring for my late wife. When tested at ***** my PSA had gone ***** – not that high but proportionately a large increase very quickly. Had I been screened each year, it could have been caught earlier. My PSA history was important to my diagnosis. Evidence Comment: I do not believe any patients, living with Stage 4 Prostate Cancer were consulted by the NSC. As 10,000 men are diagnosed each year too late for a cure, their lived experience, like mine, seems to have been ignored in considering the options. It is known that black men are twice as likely to have PCa as white men. The NSC seemed to dismiss a screening programme for black men on the grounds that not enough research had been done on why that is so. Whatever the reason, it seems illogical not to put screening in place for such a high risk group, especially as black men are less likely to come forward voluntarily for a test. Discussion comment: Limiting screening to men with the BRCA 1 and 2 seems almost a waste of time. Very few men know if they have those conditions so how will they be tested without a genetic test first? And if they do know they have it, by definition they are medically informed and probably know they are at risk of PCa. My ***** had breast cancer. My mother died from it at ***** but I don't know if I have the BRCA gene. The NSC's report said that the concern of over treatment outweighed the benefits of screening. I think that view is based on outdated data. Nowadays, the pathway after a PSA test includes an MRI scan (which have improved massively), a transperineal biopsy (far less dangerous than the previous method) and a PSMA Pet scan if needed. From those, medics and patients can discuss informed choices about treatment – it is not a headlong rush into unnecessary treatment. The conclusion seems to regard saving men from over treatment (and therefore not trusting them and doctors to take sensible choices) is more important than the 10,000 men diagnosed late each year and the 12,000 men who die each year who could be caught earlier. Recommendation comment:

	For the reasons above, I think men should be screened: Black men from 45 Men with family history from 45 All men from 50 Alternatives comment: I think GPs should be fined if they refuse to carry out a PSA test. I think GPs should have instructions to encourage men in the above risk groups to have a test. ***** should have a PSMA Pet scanner and not rely on ***** Other comments: Please see above
P339	Affected Comment: I have been diagnosed with prostate cancer. I feel it had a profound effect upon me, my family and my friends Evidence Comment: No comments about the evidence but feel it is very clear that early diagnosis can save lives as hopefully it did for me. All men should be given this chance. Discussion comment: See above. Recommendation comment: I feel screening should be available to everyone. Alternatives comment: If there are alternatives to a screening programme, the NHS and/or the government should make it clear exactly what these alternatives are and make them available to all men. Other comments:

	I feel strongly that early diagnosis is essential. It probably saved my life! It's frustrating and exasperating that both my sons find it difficult/impossible to get access to screening. I recommend that screening should be made available to anyone who wants it.
P340	Affected Comment: Yes I was diagnosed with this cancer in ***** and am still having treatment. It did affect my family from the point of view that they rallied around me and have been so supportive throughout my treatment. I have encouraged all friends and family to get checked out by having a blood test to check their PSA. I know the consensus of opinions are that the test is not conclusive but anything is better than what is currently on offer. Any form of screening is better than no screening at all. Recommendation comment: I think that the age for screening should be lowered to 40 years of age. I have ***** sons, both in their ***** and they had trouble getting their GP's to give them a blood test. In one case, it took one of my sons ***** attempts to get the doctor to do a test. If the NHS is serious in trying to eradicate or slow down the rate of this disease spreading, then surely national and early is the answer.

P341	Affected Comment: Hi guys I have a verity of interesting and chronic health conditions that I mostly have kept to myself due to the fact that I am mostly an introvert, but also that I feel it serves no logical sense to inform friends or family Evidence Comment: I am unsure Discussion comment: I have recently carried out a review of the book Overdiagnosed: Making People Sick in the Pursuit of Health by H. Gilbert Welch M.D. M.P.H. (Author), Lisa Schwartz (Author), Steve Woloshin (Author). I was advised to read it by *****, and so took up the challenge which resulted in the creation of a firm, but fair analysis of the authors thoughts which has been sent to a few relevant parties and organisations. I have recently sent a copy on ***** to your organisation who have recommended that I also fill in this section, but would sincerely recommend that you access the literature which should provide a great deal of evidence from the perspective of a male neurodivergent that should cover a high proportion of the population I am happy to resend if your having difficulty accessing it Recommendation comment: I feel that is a difficult one to initially answer on a general scale due to feedback that I have added but with regards to Prostate cancer I would unquestionably say yes Alternatives comment: * See my feedback document * Reach out to the relevant community cohort and also use various other organisations to gather information that would include; * NHS Peer Mentoring organisations ***** * Local ICB & ICS co-production groups ***** * Local Authority Community/Health and Wellbeing Champion Other comments: I am happy to have a discussion with all relevant professionals if required or failing that I sincerely hope that God will be front and centre of the consultation process

UK National Screening Committee

39 Victoria Street
London
SW1H 0EU
United Kingdom

11th January 2026

Dear Sir /Madam

I trust all is well and I would like to thank you for taking the time to read this letter, no matter what the outcome may be.

Please find attached ‘a few’ thoughts about a book I was recently recommended by my GI Consultant called Over-Diagnosed by Dr. H. Gilbert Welch. I am still unsure on their motives for recommending it, especially as I feel that it does not actually have very much in common with my personality traits and ongoing complex NHS health journey, but was up for the challenge regardless.

I hope that you can forgive me for adding a little extra reading to an already busy day, but I feel that this may become a credible piece of evidence which will inevitably compliment your research, or at least allow a joyous peripheral opportunity to know me a little more from a biological and psychological perspective.

Whilst reading the book I became more and more worried for all who may feel that it is a positive and factual reference point for how patients within the NHS should be treated, and also that it could potentially lead many a good conscientious consultant to query why they are in a role that is primarily to be in the service of others.

Please forgive me with regards to any repeated statements, literature or typing errors, as my research (initially for my consultant) has taken a great deal of significant effort and was a little rushed. I sincerely hope that you, or others in the Health Industries may be able to effectively utilise my notes for the greater good.

I also hope that whoever has the opportunity to read the book would be able to do it with an open mind, especially as I have personally been spoilt by Bessel van der Kolk’s The Body Keeps the Score.

The irony is that there has been a surprising element of learning, self-soothing and a form of healthy closure whilst reading the book.

Whilst sending you a copy of my findings, I would also not be offended if this personal research and constructive feedback has no real value at the moment, but once again would gently push that you may be able to pass it on to someone that could positively embrace its simple quest for the health and care industries to keep evolving.

Please do not hesitate to contact me if you feel there is a need for more clarity and understanding

Much regards and respect

P342	Affected Comment: I have been diagnosed with prostate cancer. This followed a discussion with a friend who has had major surgery for this disease and who made me promise that I would get tested. I got the PSA test done and a roller coaster journey started with examinations, MRI Scan, Biopsy then the 'phone call. Fortunately my cancer has been caught early and only requires close watching – which I am now gettiing. Nobody who has not gone through the process and ultimate diagnosis call can umderstand the feeling when told you have cancer. I am one of the lucky ones who was tested at my request. There is an opportunity now for a national screening programme to be set up to try to reduce deaths from this disease. Please don't waste this opportunity please vote for it's introduction. Thank you
P343	Affected Comment: I was diagnosed with prostate cancer in ***** Evidence Comment: I disagree with the evidence based on the yearly amount of PC diagnoses and deaths. Discussion comment: Screening will save lives in whatever form it takes. Recommendation comment: It should be. If it's cost preventing for example PSA tests for every man over 50 biannually then send an info pack out with the biannual bowel cancer screening. Alternatives comment: Send pc info pack along with bowel cancer screening packs.

P344	Affected Comment: I was diagnosed in ***** with prostate cancer. My PSA was ***** and the result of the biopsy was a Gleeson *****. I did not approach my doctor for a PSA test; I went for help with *****. I had none of the supposed symptoms to indicate a prostate issue. I was therefore diagnosed by accident, fortunately at an early stage with better recovery results. In my case I was able to have radiotherapy and hormone treatment. If left I would have possible needed a radical prostatectomy, the side effects of which are worse as they are more long term or even for life. Evidence Comment: I am concerned that the evidence does not truly consider the experience of those diagnosed with prostate cancer. The is especial those who were diagnosed by chance or by having fought to have a PSA test carried out. Early diagnosis is far better than waiting for symptoms that may not even develop or are missed as being related to old age or similar conditions. From the experience of the members of the prostate cancer peer support group, those who's cancer was caught earlier were diagnosed by accident, but this doesn't seem to be important. There is also too much importance being put on the Transform study, which runs for 10 years. People with a prostate need screening now to ensure their quality of life is not subject to a chance diagnosis. Discussion comment: 1. 5% of men are likely to develop prostate cancer, 25% in the case of black men. That is a huge number of people who currently have their lives subject to a medical game of Russian roulette due to the difficulty in obtaining a PSA test, assuming they are aware of prostate cancer in the first place. Whilst the PSA test does not indicate prostate cancer it does indicate a problem with the prostate that requires further investigation. To just rule it out because it doesn't diagnose cancer is idiotic, eventually it will still be used to start the journey to a diagnosis as this is the only test available currently. I would also disagree with the term 'False Positive'. As I say above, a high result indicates an issue with the prostate that requires investigation. The result does not suggest cancer is present. Mention of chemotherapy in the treatment of prostate cancer is misleading, unless the cancer has already escaped from the prostate and has metastasised. This would hopefully only be required if the initial cancer was treated in the normal range of radiotherapy, hormone or a radical prostatectomy and reoccurs later in life. Reference is made in studies to reducing mortality rates. The screening and treatment goal is not to reduce mortality; it is to reduce the loss of quality of life for everyone. Recommendation comment:

Screening should not be looked at reducing mortality but at maintaining the quality of life as best as possible, therefore early diagnosis is the desired outcome.

Until alternatives come forward screening, with the PSA test, MRI scan and biopsy, is the only option. False positives and overdiagnosis is still more desirable to the alternative, do nothing until the diagnosis is terminal and premature death is the only likely outcome.

The youngest person I know to have been diagnosed with prostate cancer was *****, generally I come across numbers diagnosed in their forties and fifties. I was diagnosed at *****.

I believe screening should be carried out at the age of 50: those at higher risk due to colour or the history of prostate cancer in the family then start screening at 40.

Depending on PSA scores, lower numbers can be monitored by yearly scans to see how the results rise.

Above a certain level, to be agreed on, refer for an MRI scan to determine if a tumour is present and where it is located if detected. From this carry out a trans perineal biopsy targeted on the location of the tumour. From the results of this further treatment can be determined. A possibility of active surveillance should be the initial course of action, especially if a Gleeson 3+3. Tests at 3 month intervals will give an indication of the growth and if further treatment is needed.

A higher score will most likely require more urgent treatment after the diagnosis as indicated above.

By monitoring and treating earlier the quality of life will be far superior to that where the diagnosis is already terminal and the treatment will need to be chemotherapy and a lifetime of castration hormone treatment. Although this can be effective the quality of life is much reduced and expensive.

Alternatives comment:

There may be many alternatives to all screening programmes, none seem to have been put forward for consideration in the case of prostate cancer.

Breast cancer still requires an initial reason to carry out a biopsy to determine if a lump is benign or cancerous.

Bowel cancer testing still refers to follow up investigation by an intrusive examination.

There are no examples of what else would be an alternative, apart from individuals going and having a PSA test done. Until there is an alternative test to the PSA test then this is still the only way of starting the treatment journey.

The NHS and Government could help by stopping making it so difficult to get diagnosed in the first place and encouraging medical professionals to carry out PSA testing.

Other comments:

I've checked the internet on bowel and breast cancer screening and neither of these actually diagnose bowel or breast cancer.

The UK bowel cancer screening test, known as the faecal immunochemical test (FIT), does not diagnose bowel cancer directly but checks for blood in stool samples, which can indicate the

presence of cancer. If blood is detected, further tests, such as a colonoscopy, are conducted to confirm a diagnosis.

The UK breast cancer screening test, known as a mammogram, is designed to detect early signs of breast cancer, but it does not provide a definitive diagnosis. If abnormalities are found during the screening, further tests such as biopsies may be needed to confirm whether cancer is present.

Why do we carry out these screening programmes that require follow-up investigation, but use the fact that the PSA test requires follow-up investigation as an excuse to deny screening?

More investigations and surveys need to be carried out amongst people who have had a diagnosis for prostate cancer to determine if they would have preferred to have been screened or have had to find out for themselves.

P345	Affected Comment: Yes Evidence Comment: ***** · Capacity: Responding as a member of the public and a concerned citizen. 1. Overall View on the Draft Recommendation I strongly object to the draft recommendation as it stands. While welcoming the move towards a targeted screening programme, the current proposal is fundamentally inequitable and lacks transparency. It creates an unjustifiable two-tier system that will exacerbate existing health disparities. 2. Response to Specific Draft Recommendations · Regarding “offer a targeted national prostate cancer screening programme to men with confirmed BRCA1 or BRCA2 gene variants”: I do not object to screening for this group. However, I object vehemently to the exclusive prioritisation of this risk category while others are excluded. · Regarding “not recommend targeted screening of Black men”: This point is the core of my objection. The rationale is contradictory. The UK NSC acknowledges Black men as a high-risk group yet denies them a targeted programme, citing a need for more evidence. Meanwhile, the proposal for BRCA carriers moves forward. This is an inconsistent application of evidential standards that results in discriminatory policy. As Prostate Cancer UK states, excluding Black men now “fail[s] to reduce long-standing inequities in diagnosis and outcomes”. · Regarding collaboration with the TRANSFORM trial: While the £42 million TRANSFORM trial is welcome, it cannot be used as justification for delaying equitable policy. The trial is designed to recruit Black men (aiming for at least 1 in 10 participants), proving both the recognised need and the possibility of inclusive research. Men’s lives cannot wait indefinitely for “perfect” evidence when a significant, known risk exists today. 1. Core Argument: Inequity and Lack of Transparency The policy creates a “concealed pathway” and an “excluded pathway.” · The Concealed Pathway: Men from ethnic groups with high BRCA prevalence (e.g., Ashkenazi Jewish heritage) gain access through a genetic criterion, masking ethnic prioritisation. · The Excluded Pathway: Black men, whose risk is based on robust demographic and clinical evidence, are explicitly denied. This approach allows healthcare providers to offer screening to one high-risk patient while telling another with comparable risk that national policy does not prioritise him. This is unacceptable. 1. Recommendations for Change The UK NSC must amend its final recommendation to ensure equity and transparency. The policy should either:

· Formally include Black men as a named, high-risk group eligible for targeted screening alongside BRCA carriers, or;

· Pause the recommendation for BRCA carriers until a truly equitable, multi-risk group pathway can be implemented simultaneously, based on the high-risk criteria the Committee itself acknowledges.

1. Conclusion

Implementing the draft recommendation in its current form would be a step backwards for public health equity. I urge the Committee to revise its position to create a fair, transparent, and just screening policy that addresses the needs of all high-risk groups without discrimination.

Submitted by,

Discussion comment:

1. Respondent Details

1. Overall View on the Draft Recommendation

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· Regarding collaboration with the TRANSFORM trial: While the £42 million TRANSFORM trial is welcome, it cannot be used as justification for delaying equitable policy. The trial is designed to recruit Black men (aiming for at least 1 in 10 participants), proving both the recognised need and the possibility of inclusive research. Men’s lives cannot wait indefinitely for “perfect” evidence when a significant, known risk exists today.

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The policy creates a “concealed pathway” and an “excluded pathway.”

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P346	Affected Comment: Yes father and son Evidence Comment: Never offered any scans or tests until I had problems now costing the NHS lots of money, false economics Discussion comment: Let's test all men that might be at risk Recommendation comment: Yes to save NHS money easier to treat if found early enough Alternatives comment: Early diagnosis Other comments: Early diagnosis Dave NHS money and save lives
P347	Affected Comment: Prostate cancer has had a profound and direct impact on my family and on me personally. In *****, my ***** *****, was diagnosed with***** prostate cancer. He had no symptoms at the time of diagnosis and later died from the disease. His diagnosis came too late for curative treatment. Only as a result of his diagnosis did I request PSA testing through my GP. My PSA levels rose over time (*****). Following MRI and biopsy in *****, prostate cancer was confirmed, and I underwent *****. At no point prior to my brother's diagnosis was proactive PSA testing discussed with me, despite my clear familial risk. Had I not persisted in requesting testing, my cancer would likely have remained undetected until a later stage. This experience demonstrates the real-world consequences of a policy that relies on symptoms or patient self-advocacy rather than proactive risk-based engagement. My brother's asymptomatic ***** diagnosis and my own delayed detection illustrate how the current approach can result in avoidable harm to individuals and families. Evidence Comment: The review places significant weight on historic concerns regarding overdiagnosis and overtreatment associated with PSA screening but does not sufficiently reflect advances in diagnostic pathways or long-term international evidence. Long-term follow-up from the European Randomised Study of Screening for Prostate Cancer (ERSPC) demonstrates a sustained reduction in prostate cancer mortality associated with PSA-

based screening over extended follow-up periods. This evidence is particularly relevant when considering targeted or risk-stratified approaches rather than population-wide screening.

In addition, the review does not appear to adequately incorporate evidence on modern diagnostic practice, including the routine use of pre-biopsy MRI, PSA density, risk calculators, and active surveillance. These developments substantially mitigate the harms that underpinned earlier screening concerns.

The review also gives insufficient attention to evidence regarding higher-risk populations, including men with first-degree relatives affected by prostate cancer, men with significant family histories of breast cancer, and Black men, who experience higher incidence and mortality. International guidelines increasingly recommend earlier or more intensive screening for these groups.

Overall, the evidence base supporting a targeted, risk-based approach appears under-represented in the review, particularly in light of modern clinical practice.

Discussion comment:

The discussion and conclusion adopt a largely binary framing of screening versus no screening, which does not adequately reflect contemporary clinical practice or policy options.

The recommendation against screening appears to prioritise avoidance of potential harms without sufficiently balancing these against the harms of late diagnosis, particularly for men at elevated risk. My brother's diagnosis with asymptomatic Stage 4 disease illustrates that reliance on symptoms is not a safe or equitable strategy.

The conclusion also underestimates the consequences of placing responsibility on individuals to request PSA testing. Many men are unaware of their risk and therefore never have an informed discussion with a clinician. This approach disproportionately disadvantages those with lower health literacy and contributes to health inequalities.

A more nuanced conclusion recognising the distinction between population-wide screening and targeted, risk-based approaches would better reflect current evidence and practice.

Recommendation comment:

I do not support blanket population-wide screening. However, I strongly believe that screening or proactive assessment should be recommended for men at elevated risk.

My own experience demonstrates why. PSA testing was only initiated after my ***** diagnosis. My PSA rose progressively over time before cancer was confirmed. Without persistence, my cancer would likely have been detected later, with worse outcomes.

PSA testing is inexpensive, and when used as part of a structured pathway incorporating MRI and active surveillance, the balance of benefits and harms is significantly improved. International practice increasingly supports informed, shared decision-making for high-risk groups rather than passive availability.

A recommendation against any form of proactive screening risks perpetuating avoidable late diagnoses and widening inequalities. A targeted, risk-based recommendation would better align with both evidence and lived reality.

Alternatives comment:

The NHS and government could take meaningful action short of introducing a full screening programme by implementing proactive risk-based measures.

These could include:

- Systematic identification of men at higher risk in primary care, including those with first-degree relatives affected by prostate cancer or strong family histories of breast cancer.
- Proactive invitations for informed discussions about PSA testing for high-risk men, rather than relying on patient self-request.
- Clear national guidance for GPs on risk stratification and referral thresholds.
- Public health messaging targeted at higher-risk groups to improve awareness

These measures would improve early detection while avoiding the harms associated with population-wide screening and would be feasible within existing NHS structures.

Other comments:

I recommend that the UK NSC:

- Explicitly differentiate between population-wide screening and targeted, risk-based approaches in its recommendations.
- Commission or support pilot programmes focused on high-risk populations to generate UK-specific evidence using modern diagnostic pathways.
- Review how familial cancer risk is assessed in practice, particularly where prostate and breast cancer histories overlap.
- Ensure equity considerations are central to future recommendations, particularly for Black men and those with inherited risk.

My brother's death and my own diagnosis demonstrate that the current approach has real human consequences. A more proactive, risk-based strategy would better protect those most at risk while remaining evidence-based.

P348	Targeted Screening for Prostate Cancer in BRCA1/BRCA2 Carriers Submitted by: ***** 1. Summary of Key Concerns I welcome the NSC's efforts to improve early detection of prostate cancer. However, the current draft recommendation — limiting targeted screening to BRCA1/2 carriers — raises significant concerns relating to: • Equality Act 2010 compliance • Human Rights Act 1998 implications • Exclusion of other clearly evidenced high-risk groups • Lack of transparency regarding modelling and equality analysis I urge the NSC to revise its approach to ensure that screening policy is both evidence-based and legally compliant. 2. Elevated Risk in Non-BRCA Groups The draft recommendation focuses exclusively on BRCA1/2 carriers. This excludes other groups with equal or greater epidemiological risk, including: Men of African and African-Caribbean heritage • 2–3× higher incidence • Double the mortality • Earlier onset and more aggressive disease patterns Men with strong family history

- First-degree relative affected = 2–3× increased risk
- Risk comparable to or exceeding BRCA-associated risk

Older men

- Age remains the strongest risk factor
- Risk rises sharply from age 50 onwards

The NSC's draft does not explain why BRCA status is prioritised over these well-established risk factors.

3. Equality Act 2010 – Public Sector Equality Duty (PSED)

Under section 149, public authorities must have due regard to:

- Eliminating discrimination
- Advancing equality of opportunity
- Reducing inequalities of outcome
- Removing disadvantages linked to protected characteristics (including race and age)

Restricting screening to BRCA carriers risks indirect discrimination under section 19, as it disproportionately excludes:

- Black men (a protected racial group)
- Older men at highest risk

No Equality Impact Assessment (EqIA) has been published, and the consultation documents do not demonstrate how the PSED has been discharged.

4. Human Rights Act 1998 – Articles 2 and 14 ECHR

Article 2 – Right to Life

The state must take reasonable steps to protect life where serious, well-known risks exist.

Article 14 – Non-Discrimination

Policies must not disproportionately disadvantage groups without objective justification.

Given the significantly higher mortality in Black men and those with strong family history, a screening model that excludes these groups may engage both Articles 2 and 14.

The consultation materials do not address these obligations.

5. Comparison with Other UK Screening Programmes

Other national screening programmes already incorporate multi-factorial risk stratification, including:

- Breast cancer screening (family history, age, genetic risk)
- AAA screening (sex-specific risk)
- Bowel cancer screening (age-based thresholds)

There is clear precedent for screening models that integrate genetic, demographic, and familial risk factors.

6. Concerns About the Modelling

The NSC commissioned modelling from SCHARR, but the consultation does not clarify whether the modelling:

- Included ethnicity-based risk
- Included family-history-based risk
- Assessed combined risk models
- Evaluated inequality impacts
- Considered cost-effectiveness of multi-factorial targeting

Without transparency, the evidence base is incomplete.

7. Recommendations

I respectfully request that the NSC:

1. Publish a full Equality Impact Assessment (EqIA)

This is essential to demonstrate compliance with the Equality Act 2010.

2. Expand modelling to include other high-risk groups

Specifically:

- Men of African and African-Caribbean heritage
- Men with strong family history
- Older men
- Combined risk-stratification models

3. Re-evaluate the draft recommendation in light of equality and human-rights duties

	A screening model that excludes the highest-risk racial group requires explicit justification. 4. Consider a multi-factorial targeted screening programme This would align with existing UK screening practice and better reflect the evidence. 5. Publish all modelling assumptions and parameters Transparency is essential for public and scientific scrutiny. 8. Conclusion The proposal to introduce targeted screening for BRCA1/2 carriers is a positive step, but it is not sufficient to address the full landscape of prostate cancer risk or the statutory duties owed under equality and human-rights law. A more inclusive, evidence-based, and legally compliant approach is required — one that recognises the elevated risks faced by men of African heritage, those with strong family history, and older men, and that ensures equitable access to early detection. I urge the NSC to revise its draft recommendation accordingly.

P349	Affected Comment: I have had prostate cancer. Discussion comment: The conclusion not to have a full screening programme is wrong. I have survived prostate cancer. Thankfully I caught it through testing and was successfully treated with a radical prostatectomy. I did not have any symptoms, it was only because I took myself to my GP each year and insisted on a PSA test that I caught my cancer. It turned out to be aggressive and there is every chance it would have killed me if I had not done self screening. I have had the tests since I was ***** and I caught it at *****. I did the tests as prostate cancer killed my grandfather. My ***** , and his ***** , have also had it but both caught it by chance and were successfully treated. I did my research and looked after myself. Too many men are not. Too many men who could have been diagnosed and treated are instead dying. Too many avoidable cases like Chris Hoy. Prostate Cancer UK run campaigns to get all men over 50, black men over 45 and any men over 40 with a family history to get yearly checks. Why does this need to be a charity appeal, the NHS should implement this as a screening. We have an increasing rate of men being diagnosed. We have increasingly better diagnosis, especially with DRE and MRI scans. I believe the tipping point of putting men through unnecessary treatment against saving mens lives has been passed. The choice of having the test or proceeding with treatments will still be an informed decision by each man, nothing is forced on them. But let them decide. Recommendation comment: Bases on personal experience of having had prostate cancer, I strongly believe there should be a full screening programme. I have survived prostate cancer. Thankfully I caught it through testing and was successfully treated with a radical prostatectomy. I did not have any symptoms, it was only because I took myself to my GP each year and insisted on a PSA test that I caught my cancer. It turned out to be aggressive and there is every chance it would have killed me if I had not done self screening. I have had the tests since I was ***** and I caught it at *****. I did the tests as prostate cancer killed my grandfather. My ***** , and his ***** , have also had it but both caught it by chance and were successfully treated. I did my research and looked after myself. Too many men are not. Too many men who could have been diagnosed and treated are instead dying. Too many avoidable cases like Chris Hoy. Prostate Cancer UK run campaigns to get all men over 50, black men over 45 and any men over 40 with a family history to get yearly checks. Why does this need to be a charity appeal, the NHS should implement this as a screening.

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P350	Affected Comment: My father passed away at *****. I think there should be a national programme from aged 50

P351	Affected Comment: I have Prostate Cancer. It was diagnosed only after significant symptoms became apparent. There were delays in the process of diagnosis and treatment: ***** month delay from first requesting a PSA test from my GP ***** delay in first referral to the Urologists as no appointments were available ***** delay between having an MRI and receiving results ***** delay in receiving a positive cancer diagnosis, only found out by looking at my patient record and then had to use the Hospital's PALS service to get the Urologists to contact me with an appointment to discuss what could be done. The combined delays and having to chase for follow-ups was a highly stressful process. As the Cancer was well established and considering that I also have*****, I was left with only one treatment option – Radical Prostatectomy. This has led to ongoing incontinence and erectile disfunction. Earlier diagnosis and treatment would have made more treatment options available to me, many of which would not have had such severe side effects. Evidence Comment: I am not an expert in this area, but my entire working life has been in *****, as a result I am used to having my decisions made on the basis of fact. I believe that undisputed facts exist: 1 in 8 Men will develop Prostate Cancer, 1 in 4 for certain ethnic groups Genetic predisposition on the basis of BRCA gene mutation. Why on the basis of these facts alone would you not establish a properly targeted screening process? Discussion comment: It appears that the decision has been taken to kick a final decision down the road to be worried about at a later date. How many need to suffer or die before anything is done? Recommendation comment: I believe targeted, risk-based screening should be a first step towards a wider screening programme. I also believe that men at higher risk deserve earlier assessment and treatment. Yes there are risks of overdiagnosis or overly harsh treatment, but surely the patients should be given the choice?

Alternatives comment:

Organised prostate cancer testing must be the place to start. For example the Swedish model.

Personal risk assessment should be carried out at a relatively early age 40's ? and take account of family history of both Male and Female Cancers.

Other comments:

The following points have been copied and pasted from another source, but I sincerely believe that they represent my views as a Cancer sufferer:

- * The need to keep policy under active review as new evidence comes to light
- * The importance of involving patients and communities in future decisions
- * A call for urgency, while still being evidence-led
- * A reminder that behind every statistic is a person and a family

Further to the last point, despite having had radical treatment that has significantly damaged my way of life, I still live every day with Cancer. It has not gone. The prognosis may well have been better if there were an adequate screening process in place earlier.

P352

I was diagnosed with ***** prostate cancer in ***** at age *****. PSA ***** , Gleason ***** , mets throughout my skeleton. I started ***** training for ***** . In ***** I started feeling a "groin strain" that got progressively worse. I consulted with a ***** and arranged an MRI scan. On seeing the scan, he sent me for blood tests and a chest x-Ray and booked me in the following day for a full body CT scan. In the evening of the scan, he called me to tell me that he was 99% certain I had prostate cancer. Ten days of further tests including trans rectal biopsy and bone scans and it was confirmed as incurable metastatic prostate cancer and I was given a worst-case prognosis of 2-3 years. At the first appointment with the urologist my wife asked how long he thought I'd had the cancer developing and he said ***** years. I'd had no symptoms at all until the groin strain started in the *****.

I was furious to later find out that I'd had a right to a PSA blood test from age 50 and if I'd been regularly tested from 50-60 there's a very good chance that my cancer would have been diagnosed earlier when still curable.

The impact on my life and on health care systems has been horrendous. I lost my self-esteem (loss of erectile function and body image does that). I lost substantial sums of money selling business assets at the wrong time because I could no longer cope with the stress of work and cancer. Keeping me alive to date has cost, initially, my insurers (they had to go because my income dropped by 80%) and latterly the NHS, c. ***** to keep me alive to date. That will only get worse as my health deteriorates. My mental health deteriorated massively. It was terrifying being told you've got incurable cancer and maybe only ***** years to live and I ended up having a mental breakdown.

The impact on my family has been dreadful. My wife says my cancer has robbed us of the retirement we expected to have together and there is no experience in life that can in any way be worse than telling your children and grandchildren that you are dying.

All of this might have been avoided if I'd known about my right to have a PSA test at age 50. Reliance on awareness alone is simply not acceptable with 12,000 men dying every year!

Evidence Comment:

We know that c. 11,000 men are diagnosed too late in the UK every year, the ultimate harm. The NPCA told us that 383 men with low grade prostate cancer had radical treatment (potentially harmed) and that c. 2,000 men had to have surgical interventions or procedures within 2 years of radical treatment. It seems that the harm from over treatment is relatively low compared to the ultimate harm of death and the huge cost involved in treating men diagnosed too late. I feel very strongly that the harms of late diagnosis and the impact on men and their families are significantly under represented when considering whether there should be a screening programme. If men are being harmed by over-treatment, then the way to stop this happening is to make sure health care professionals communicate better with their patients to ensure that men are not treated unnecessarily.

At this stage, with the TRANSFORM trial now recruiting, and evidence suggesting that overtreatment is much reduced from 10 years ago and even more so in the last 5 years, the decision not to allow targeted screening for black men and men with a family history seems to me to be very disconnected from real life experience and what I hear from men living with prostate cancer in my roles as *****. I feel very strongly that the committee has given insufficient weight to lived experience.

The decision not to allow targeted screening massively perpetuates health care inequalities as we know that black men and men from poorer socioeconomic backgrounds fare much worse than others because we currently rely way too much on men needing to be aware of their risk

and then being proactive about it. My experience demonstrates that many GPs don't follow their guidelines on testing either symptomatic or asymptomatic men because they refuse men their right to a PSA blood test after counselling. Therefore, the decision to refuse screening, coupled with men needing to make informed decisions on getting tested and some GP's refusing men tests, is leading to many more deaths than necessary. Alarming it seems that some GP's are doubling down on refusing men PSA tests citing your decision as the reason!

It also appears that data has been inconsistently applied across the cohorts of men who would benefit from screening, giving insufficient consideration of the impact on high-risk cohorts.

Suggesting screening for men with the BRCA mutation feels very much like a political rather than an evidence-based decision, a sop to say that you have done something and given politicians a get out clause. The cohort is tiny and virtually impossible to identify without genetic testing and yet way more black men and men with a family history are at a similar high risk as men with BRCA, are more easily identifiable and you have decided to recommend against screening for them.

Discussion comment:

As I have outlined above the decision to screen a tiny cohort (BRCA) produces miniscule benefit in early diagnosis of prostate cancer. It feels ridiculously cautious when the benefits of targeted screening of black men and men with a family history would save way more lives. It's very concerning that you have used uncertainty as a reason to recommend against screening. It would be remarkable to accept that nothing has happened, apart from 12,000 men dying every year in the UK, in decades to satisfy your uncertainty that has clearly led to inaction.

It's deeply concerning that rates of late diagnosis are rising because nothing has improved on screening policy for decades. The variances in late diagnosis geographically are quite staggering (35% of men diagnosed in Scotland) and really emphasises health inequalities as it's very clear that, without a screening programme, men at most risk are not getting tested via the informed choice route and are therefore faring much worse. It simply isn't acceptable that men from poorer socioeconomic backgrounds are dying because of lack of awareness and ability to engage with HCP's. Similarly, it's not acceptable that men from different ethnic backgrounds, including black men at twice the risk of white men, are faring really badly with late diagnosis and early death.

I also found it very concerning that the NSC didn't engage with men with lived experience and their families. As a ***** and *****, I can assure you that the vast majority of people I engage with, who have been impacted by prostate cancer, real lived experience, disagree very strongly with your decision and think it will lead to more suffering from late diagnosis and the ultimate harm of death stealing men's lives from their loved ones. Denying men the opportunity to see grandchildren come into their lives and missing those really important life milestones because a simple £20 blood test is being denied to them.

In respect of screening men with the BRCA mutation you have proposed stopping testing at age 61 and yet nearly 50% of cancers detected in BRCA carriers are aged 61-69. You've also recommended screening every 2 years despite evidence (IMPACT trial) suggesting annual screening to avoid the risk that an aggressive cancer could be allowed to grow unchecked for a whole year.

It's difficult to reach any conclusion other than that your decision produces a sub optimal outcome based on saving money rather than lives. It's alarming that you constantly call for more evidence and yet ignore evidence available.

Recommendation comment:

I don't think that we are ready yet for population wide screening but not because it's wrong to do so. The issue with population wide screening is the pressure it would put on ill-prepared health care systems. Just writing those words shocks me because we've had over two decades to be prepared for screening since USPSTF first opined that population screening shouldn't take place. It's quite staggering that, in those two plus decades, no progress has been made that would lead to a positive decision on screening and health care systems haven't been readied for a screening programme. All that has happened in 25 years is that another 300,000 men have died in the UK alone, ripping apart 300,000 families when a good proportion of those lives could be saved by screening.

At this stage I do believe that there is sufficient evidence to support a targeted screening programme for black men and men with a family history and that this should have been recommended as a first step towards a population wide screening programme. It's quite clear that men at higher risk have been neglected for decades and deserve much earlier diagnosis and clearer access to PSA tests.

Whilst accepting that there are potential risks of harm from overtreatment because of screening, much of that harm has been mitigated with the improved diagnostic pathway of mpMRI, use of trans perineal biopsy and use of active surveillance for low risk/low grade cancer. Those harms can be reduced to the point of being negligible by working with HCPs to ensure that the regions where too many men are being treated radically for low grade cancer are brought into line with best practice and that care is delivered consistently, thus ensuring harm becomes a non-issue.

It's greatly concerning that you have not engaged with men with lived experience and indeed no one involved in the decision had lived experience. Such engagement would almost certainly have resulted in you hearing that men are happy to accept relatively low risk of harm in return for being rid of their cancer. All decisions such as this needs PPI input but you had absolutely none.

Alternatives comment:

The current system of informed choice simply doesn't work. It exacerbates all the health care inequalities that are already noted such as black men and men from poorer socioeconomic backgrounds faring so much worse. Way too much reliance is placed on awareness and that's why black men and those from poorer backgrounds fare so badly. It also relies too much on GP's not acting as barriers to men getting tested. It's quite staggering that GP's refuse to follow their own guidelines on testing men.

It's very clear that GP guidelines need to be strengthened so that they are encouraged to engage with men on testing rather than being told not to.

On behalf of *****, I wrote to all ***** in England to highlight the fact that some GP's are flatly refusing to give men PSA tests and there is already evidence that your decision on screening has led to some GP's doubling down on refusing tests, citing your decision as the reason. My letters have led to me presenting to *****, in conjunction with *****, on the subject of *****. This led to immediate change in policy ***** in *****. This is significant as *****.

GP education on prostate cancer needs significantly improving and should be compulsory.

It's also absolutely fundamental that we need better public information on prostate cancer risk rather than relying on the Turnbull/Fry, Sir Chris Hoy impact.

Development of an online informed decision tool for PSA testing would take away the need for GPs to have to consult all men when they request a test. Thankfully such a tool is being developed in Greater Manchester and this should be rolled out across the country and should give an easy access to a PSA test that doesn't need to involve a GP, the blood test can be done by GP support staff. It should be made compulsory for GPs to give a PSA test to men who have used the informed decision tool.

Guidance on PSA testing needs to be improved and consistently applied. That simply isn't happening currently.

Ultimately you need to do so much more to ensure that health care inequalities that I have already outlined are not perpetuated.

We desperately need structured PSA testing, as has been modelled in Sweden, to replace the current ludicrous ad hoc system in the UK. Community screening events such as those organised by charities like ***** and ***** support groups have identified significant numbers of men with prostate cancer and saved many lives. Rolling out community-based testing would ensure that we maximise the number of cases of men diagnosed until such time as a screening programme is recommended.

Other comments:

I understand that screening decisions are complex but I want my lived experience, that has been horrendous, and my knowledge and interaction with other men to be considered alongside the clinical evidence.

Without a screening programme all we are left with is awareness as an entry point to getting tested and relying on that simply perpetuates health care inequalities that I've already highlighted.

This daily telegraph article and its headline emphasises that relying on reluctant GPs to agree to test men is totally unacceptable and creates significant barriers to early diagnosis.

<https://www.telegraph.co.uk/christmas-charity-appeal/2025/12/23/diagnosed-prostate-cancer-two-days-christmas/>

"I think my doctor's flawed clinical reasoning probably came from the national policy around screening, but also a lack of confidence around contextualising a patient's entire history,"

As a man living with terminal prostate cancer who would almost certainly have had a different outcome if there had been a screening programme, it seems to me that all the eggs have been loaded into the TRANSFORM basket. Waiting for outcomes from TRANSFORM is not acceptable. If the trial produces some evidence in say 3 years and then you take 2 years to consider it, it will then take another 2-4 years to implement a screening programme. That's somewhere in the region of 8 years in which another 96,000 lives will be lost in the UK. If it takes TRANSFORM say 10 years to produce evidence you constantly ask for then that's 180,000 lives lost. Sitting back and doing nothing is a terrible option. Instead, you should be proposing targeted pilot screening, for those at highest risk, alongside TRANSFORM so that the health systems in the UK are ready for population wide screening to come which it ultimately must.

You need to keep policy under constant urgent review as every shred of evidence comes to light and not just wait for TRANSFORM. You must involve PPI in all decisions moving forward and learn from lived experience.

Ultimately behind every statistic/piece of data is a man like me and families like mine. Men and families whose lives have been decimated by being diagnosed too late. Families that have been ripped apart.

It's now time for action and not for sitting back and watching more men die. Please be brave and bold and do something to save our lives."

P353	Affected Comment: I write as this condition, prostate cancer has affected, I note the decision was to test men with a BRCA 1 and BRAC2 gene. It was on by chance I had my diagnosis after a ***** had a terminal diagnosis of prostate diagnosis. My result proved I had a level ***** even without symptoms. I had a journey of active journey of active surveillance form ***** until ***** where I had ***** consecutive increase reading in PSA result. I had a choice of treatment, which most men are not afforded. My son who is age ***** will NOT be afforded the privilege of screening, as an Afro-Caribbean is more than twice likely to experience prostate cancer. In most cases prostate cancer is diagnosed when it too late for treatment. The NICE guidelines also need to be to allow GP facilitate those men who are at high risk, like black who are 1 in 4 at risk and those men who are at risk due to risk from family history. False positive is less risky than the amount of men dying annually when treatment could have been offered. I proposed a re think allowing black men, as well as other men who are at high risk to be tested early or earlier. I envisage that there should not be any extra cost in permitting prostrating cancer screening from age 45/50 on wards. Thanks retrospective outlook Evidence Comment: Prostate cancer/ Prostate cancer research has identified that 12,000 die needlessly every year. Prostate cancer research has initiated there TRANSFORM project which will be even more informative In my view there appear to be some inequality in health provision where men form different ethnicity are treated differently and not offered the treatment they deserve Discussion comment: I would like to ask how many men know whether they are BRCA1 or BRAC2 gene. There needs to be mass health promotion from primary school level through to pension age Recommendation comment: Screening should be available to black men who are twice as likely to experience prostate cancer and other men who are at risk due to family history of other related cancer. To make themselves avail of the treatment available to live a longer life with friends and family Alternatives comment: Health promotion to dispel the myths, any research that is available to identify the root cause. I note the government first ever men's health strategy and applaud this, which should involve health care professionals, celebrities, sport organisations, people from the Arts such as musicians and footballers to name but a few Other comments: Encourage others who have experienced prostate cancer to be part of the national screening committee and listen interested parties like Prostate cancer UK and other such parties

P354	Affected Comment: It affects me – I have stage **** prostate cancer and a friend of mine died of the disease recently. However, I am thankful and fortunate that initially it was picked up early in ***** when I was ***** and it was considered curable. If it had been picked up later then it is highly probable that I would have been dead years ago and missed out on many joyous occasions and life events. I was diagnosed stage ***** in *****. Evidence Comment: I don't think sufficient weight was placed on the lived experience of men affected by the disease. My cancer was picked up by chance in ***** when I was ***** I had a biopsy as part of the investigation and suffered no ill effects- I would happily submit to a biopsy again, although I understand that MRIs have largely replaced these. I was advised to have a prostatectomy which I did since at that time the cancer was felt to be curable. Since then I have suffered from urinary incontinence. I am more than happy to have this as a tradeoff for still being alive. There is much talk about overtreatment and the harms this causes but for me this pales into insignificance against the greatest harm of all, which is being dead prematurely due to the cancer not being picked up early. As my PSA started rising a few years after my prostatectomy I had radiotherapy in ***** which knocked the cancer back again. I had no problems or side effects with the RT and would have it again. Unfortunately my cancer was not completely cured and I was diagnosed as stage 4 metastatic in *****. Since then I have been on hormone therapy and fortunately have responded well to it and live a good quality life. The prostatectomy and the hormone therapy have left me impotent, but for me the main thing is that I am alive and enjoying life. In ***** I attended the *****. Without my cancer being picked up early I would not have been around to celebrate ***** and am hoping to become a *****. How many thousands of men do not live to celebrate their ***** and see their grandchildren because there is no screening programme to diagnose their cancer as an early stage. I am still alive ***** years after my cancer was diagnosed because it was caught early- how many men can say that? (NEXT COMMENTS BELONG UNDER "SCREENING" BUT CAN'T CUT AND PASTE -SORRY) I am in favour of screening – the PSA test may be imperfect as a first line screening tool but until something better is developed then we should make use of it. I believe that many of the 12,000 men who die of the disease each year in the UK would be spared a premature and often painful death if a screening programme were in place. I accept that some men would slip through the net due to "false negatives" from a PSA test screening programme but thousands would be saved due to early diagnosis. I consider this preferable to not having a screening programme and sentencing 12,000 men each year to a premature death. I would start screening from age 50 as the large majority affected by the disease are above this age, although I understand that this would be too late for some unfortunate men Discussion comment: I disagree with the decision not to have a screening programme as this sentences 12,000 men each year to a premature and often agonising death which in many cases robs them of their retirement and many joyous experiences in later life like their children's weddings and seeing their grandchildren Recommendation comment: SEE COMMENTS IN EARLIER SECTION Alternatives comment:

	I support ***** at their awareness days. It makes my blood boil when I speak to men over 50 who tell me their GP has refused them a PSA test as this is against NHS guidelines which state that GPS should discuss such a request with the patient, not flatly refuse it. The individual trusts invariably say that this is not an issue in their trust and GPS do not do this. I know from my own experience at these awareness days that this is not true. Even though the PSA tests may not be totally reliable I find it scandalous that GPS refuse a £20 test which could save a man's life and much physical and mental anguish as well as causing heartache for the man's family if cancer is diagnosed further down the line after it has become metastatic. Some GPS also appear fixated on asking if the patient has any symptoms, such as frequent urination, before agreeing to the PSA test. Such thinking is downright wrong – I had no symptoms before my diagnosis and I know many other men who say the same even though I do accept that some men have symptoms. Please ensure the GPS follow NHS guidelines regarding PSA requests in future

P355	Affected Comment: Yes – I was diagnosed with prostate cancer after several doctor and hospital visits that failed to disguise the condition. It was eventually spotted during a biopsy that I insisted on but I had to pay for ablation via ***** as I was not happy with Active surveillance. ***** years later I am pleased to say I am still free of Prostate Cancer. Evidence Comment: My view is that it is a cost consideration because 7 out of 8 men may not have prostate cancer. This is not helpful to the 1 in 8 who do have prostate cancer. The NHS must consider treating sooner by testing regularly to avoid stage 3 or 4 prostate which is rarely cured and needs huge NHS resources to maintain treatment and clinical staff time, especially with younger men. Discussion comment: I understand some of their reasons but consider it to be unfair and discriminatory to men. Thankfully there are many in the medical profession who favour early screening as a way to reduce prostate cancer deaths in men. Recommendation comment: I feel screening SHOULD be recommended because like breast and ovarian cancer screening IT DOES save lives. Alternatives comment: Once diagnosed, screening is too late. Prostate cancer sufferers need the NHS to offer all forms of treatment in all counties because at present it is a post code lottery, especially relating to Focal Therapy. Other comments: My belief is that after a PSA test an MRI scan should follow with a biopsy following post MRI and not before. Active surveillance seems wrong as one would not do this for breast, bowel or ovarian cancer, so why do this for Prostate Cancer. Finally, doctors need to be aware that Prostate cancer rarely has symptoms in its early and treatable stages. ***** cancer charity has noticed a large increase in men under 60 being diagnosed from their free PSA test, despite being told by their doctor to come back when they have symptoms. SHOCKING !

P356	Affected Comment: Yes my cousins. Evidence Comment: N/a Discussion comment: N/a Recommendation comment: Screening should be recommended for 50 and up (standard) just like mammograms, colonoscopies and for any other cancers that are common and beatable if caught early. With the odds of 1 of 2 people getting cancer in their lifetime, this should be a priority. It can save lives. With the risk that it may show a false positive, the test could be run again.
P357	Affected Comment: Yes. It has I had no symptoms. I request a PSA test be added to my annual blood test. Here I am ***** month on PSA score *****. MIR indicated areas of concern Biopsy confirmed ***** cancer tumours Postrate removed ***** Now in recovery. Had I not asked this would have gone undetected!!!! Evidence Comment: No But they need to understand how this affects our life's. Go a day in the shoes of those that have been effected. Discussion comment: This has to be taken more seriously for all men. It should be a standard practice for testing to be undertaken. Recommendation comment:

	Should be recommended. How many others could be or have been in my position. ?? This is a killer and if not given the full respect it needs to ensure that all men are given the chance to be screened how many lives need to be unnecessarily lost due to the lack of As above systems are not always there and had I not requested and gone through the process I may have been one of them being caught too late. Alternatives comment: No comment. Other comments: No. All as above
P358	Affected Comment: My father died ***** yrs ago with ***** cancer which was caused by the spread of cancer which began in his prostate..my brother has had to have a check up due to his high numbers which they have been checking on due to my father..his scan wasn't any help which led to a biopsy which thankfully proved he was clear but I know the worry he had before hand..he was older than ***** but I think due to my father having it I think early checks should be especially if in family already.. Recommendation comment: We are always told early intervention is the key to a chance of a cure..why then should there be an age where you can only start with checks..surely you should be encouraging men to go early as sir Chris how proved..especially when other male family members have had it..if it were women we would expect it to be so..
P359	Affected Comment: My father has prostate cancer. Recommendation comment: Screening should be recommend.

	My father's cancer was only found due to him having a gene which increased his risk, and made screening available. It should be available to everybody.
P360	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: It should be recommended because it can help people. Alternatives comment: I don't think so Other comments: No
P361	Affected Comment: No Evidence Comment: None Discussion comment: No Recommendation comment: Yes so it can be treated earlier Alternatives comment: Chemotherapy Other comments:

	No
P362	Affected Comment: None Evidence Comment: None at all Discussion comment: None Recommendation comment: Yes because it gets you ready for the future Alternatives comment: Finding out the history Other comments: None
P363	Affected Comment: Not yet, but friends family

P364	Affected Comment: No Evidence Comment: None Discussion comment: None Recommendation comment: Not recommended as diagnosis of other faster growing cancer should be prioritised. Alternatives comment: Awareness campaign Other comments: None
P365	Affected Comment: No it hasn't Evidence Comment: Not really Discussion comment: Nope Recommendation comment: I think it should be recommended because it could save your life one day Alternatives comment: Not sure Other comments: No
P366	Affected Comment:

	It hasn't
P367	Affected Comment: No Evidence Comment: No Recommendation comment: Yes, because it allows for the cancer to be found earlier on so that it does not have the opportunity to grow and become more life threatening
P368	Affected Comment: No Evidence Comment: No Discussion comment: I think it is good and will save lives Recommendation comment: It should early detection will save lives Alternatives comment: Better education Other comments: Better diet and more checks

P369	Affected Comment: They have not been affected. Evidence Comment: I think you could explain it deeper. Discussion comment: I recommend you explain it a bit better. Recommendation comment: Yes so men who have it can treat it earlier. Alternatives comment: They could make there appointment as soon as possible. Other comments: No I think other than that it was very detailed and descriptive.
P370	Affected Comment: No Evidence Comment: No Recommendation comment: Yes
P371	Affected Comment: It has not affected my family or friends yet of what I heard of Evidence Comment: I don't know any evidence missed and not sure if there was Discussion comment: Not really has any questions about the review about this and the discussion, conclusion of anything Recommendation comment:

	It can cause bleeding and infections and bad side effects which could be dangerous while screening Alternatives comment: Trying to make it more secure to the patient and leading a really bad effect Other comments: I think it's fine I have no recommendations that I have thinking
P372	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: Yes because it will help people Alternatives comment: Not sure Other comments: No
P373	Affected Comment: We didn't know stuff then we get in trouble Evidence Comment: No Discussion comment: Ni Recommendation comment:

	It would be recommended because how are we going to get explore stuff Alternatives comment: Screen time Other comments: No
P374	Affected Comment: Yes my grandad Evidence Comment: No Discussion comment: No Recommendation comment: Definately should be approved. This is so important and could save lives and detect earlier
P375	Evidence Comment: No I dont Discussion comment: No Recommendation comment: It should to raise awareness Other comments: No
P376	Affected Comment: No it's not affected anyone I know

	Other comments: N
P377	Affected Comment: I have an acquaintance affected. Also I have many male relatives Evidence Comment: Not applicable Discussion comment: All recent research and drug development should be considered but early screening in my opinion is imperative Recommendation comment: It should because more information has never been a bad thing Alternatives comment: I don't know
P378	Affected Comment: Not to make knowledge. Evidence Comment: No Discussion comment: No Recommendation comment: It should be recommended as a way to increase survival rates Alternatives comment: No comment Other comments: No

P379	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: No Alternatives comment: Idk Other comments: No
P380	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: Yes. For earlier detection Alternatives comment: Unsure Other comments: No

P381	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: Should as it's useful Alternatives comment: No Other comments: No
P382	Affected Comment: No one in my family has experience this. Evidence Comment: No i dont think there was any thing missed. Discussion comment: Nope Recommendation comment: I think it should because we should use it to raise awareness and to help other people that are going through it. Alternatives comment: Maybe give them money to help for any treatments/surgeries. Other comments: Nope thats all.

P383	Affected Comment: Grandad has prostate cancer Recommendation comment: Yes,would help early detection
P384	Affected Comment: Not that i know of. Evidence Comment: Not really Discussion comment: I think it is important. Recommendation comment: I think it should be recomendad because prostate cancer can kill and has killed lots of people Alternatives comment: Im not sure. Other comments: No.
P385	Recommendation comment: Yes,I think screening should be recommended because It would prevent missed cases and prevent a lot of deaths

Affected Comment:

I was diagnosed in ***** at the age of *****. It was only just caught in time as the cancer had just exited the prostate. I was first tested in ***** as my father was diagnosed and was aware of the higher genetic risk. I have never had any symptoms. My PSA was normal. I then did not remember to retest as I was commuting and arranging doctor appointments was difficult. My brother had raised PSA in ***** and was and still is under active monitoring. My PSA was raised but not high, but I insisted in progressing along the diagnosis route of MRI and biopsy. The cancer was bad enough to require treatment. I could not have radiotherapy owing to a history of *****. I had the prostate removed by *****

The lack of a screening program meant that i was dependent on self testing and the support of my family especially my brother.

The early detection and treatment reduced the severity of the side effects, I was continent from day one and have some erectile dysfunction, managed with the use of drugs. This means the mental and emotional impact on both my wife and I was reduced.

I truly believe the the early treatment is the only reason I am alive today.

I have ***** sons and my consultant has recommended they start being tested from the age of 40 as I was diagnosed so young. Without a screening program they will have to arrange this themselves.

Evidence Comment:

The review seems to be behind the curve in the level of unnecessary treatment and false positives. No treatment occurs until a PSA test, MRI and biopsy are performed. Biopsies are only performed if the MRI suggests it is required. Additionally, with appropriate education and providing full information on the positives and negatives of treatment throughout the screening journey, means that men can always opt out of the process, including treatment at any point if they feel that suits their personal situation.

Biopsies are now much less dangerous or invasive as they are now done via the perineum rather than through the bowel wall.

This diagnostic journey has vastly reduced the incidence of unnecessary treatment. Current breast and cervical screening programs include levels of false negatives and positives and perhaps unnecessary treatment so surely the same should apply to a prostate screening program.

The review seems to believe that unnecessary treatment can lead to incontinence and erectile dysfunction, however this is also the same effect of leaving prostate cancer undetected and untreated. the earlier it is treated the lower the chance of these side effects.

The review also talks about the mental impact of the screening process. This can be rectified by educating men on the whole diagnostic journey, a high PSA does not mean cancer, but it could identify other prostate health issues, and that cancer will only be confirmed following scans and biopsies.

	In fact a full educational program is needed as many men do not realise that the initial test is a PSA blood test. they believe the first stage is a digital rectum examination and this prevents them speaking to their doctor. Discussion comment: The screening committee talks about testing for people with the BRCA gene. However, our health records will not have this information readily available. A full genetic testing program would be required to identify those with the BRCA gene. It would be more effective and cheaper to just have a full prostate screening program. I would like to know if any of the panel, or their partners have their PSA tests regularly monitored, and if so why do they believe what works for them is not appropriate for the general population. Recommendation comment: A screening program should be recommended. To save lives. To facilitate earlier detection and treatment thus reducing the incidence of side effects such as erectile dysfunction and incontinence, To reduce the costs of prescribing expensive drugs that are required for late detected advanced prostate cancer patients. Other countries already have or are introducing screening programs, such as France. Are we willing to accept that our medical infrastructure is less developed than these countries? Alternatives comment: It appears that most of the research into potentially better tests for prostate cancer are only funded by charities such as Movember and PCUK. If the government and the screening committee really believe that there should be a better screening test (for the most diagnosed cancer in the UK) then they should be fully funding such research. Other comments: In order for the screening program to be a success, the government needs to invest in better infrastructure. In particular, the NHS needs more specialist MRI capability and capacity.
P387	Affected Comment: No it hasn't

P388	Affected Comment: My grandad died of liver cancer Evidence Comment: No Discussion comment: No Recommendation comment: Not sure Alternatives comment: Not shure Other comments: No
P389	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: It should none as it can help people Alternatives comment: Make it well known and not have stigma Other comments: No
P390	Affected Comment:

	My grandma has had cancer and is having treatment soon.
P391	Other comments: No
P392	Affected Comment: My family Recommendation comment: I think screening should be recommended because it's important to know early if you have cancer. Alternatives comment: Easier access to GP appointments
P393	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: Yes because other people can see Alternatives comment: Treatment Other comments: No

P394	Affected Comment: ***** says it hasn't affected him at all. ***** remains unaware of wider implications in his immediate family. Evidence Comment: No no comment Discussion comment: No comment Recommendation comment: No comment Alternatives comment: unsure Other comments: No
P395	Affected Comment: No immediate family or friends. Evidence Comment: No Discussion comment: No Recommendation comment: Screening should be recommended – Early detection and prevention is always better. Alternatives comment: See people who need appointments quicker. Waiting times are too long. Other comments: No.

P396	Affected Comment: Not yet. Fortunately. Recommendation comment: It should be recommended to all men. Alternatives comment: * free testing upon request (men of any age) Other comments: I believe that I should be tested at a younger age as a young man myself I could have it in my 20s even, and it wouldn't be found out until it's too late and I believe this could save a lot of the men in this country. Because yes it is more likely as an older man but it's still a possibility for every young man in this country.
P397	Affected Comment: As far as I know this condition has not affected me or anyone around me, however I know that this is a problem that should be resolved. Evidence Comment: I have no comments on any evidence considered by the UK NSC in the review. Discussion comment: I have got no comments. Recommendation comment: I think that screening should because if someone has got prostate cancer and doesn't know then they could get early treatment because of screening to prevent it getting worse. Alternatives comment: I am not sure on what other methods you could use. I feel like screening is the best method. Other comments: I have got no other recommendations.

P398	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: No Alternatives comment: No Other comments: No
P399	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: Should Alternatives comment: Raise more awareness of early symptoms Other comments: Make the screening process mandatory

P400	Affected Comment: Not sure. Evidence Comment: No I do not. Discussion comment: There are a lot of risks, however if it is improved to give more accurate results it could become even better although it is already a good idea. Recommendation comment: It should be recommend since it is more reliable than a standard cancer test. Alternatives comment: Improve current techniques for detecting and destroying specific cancerous cells. Other comments: Try and improve the design if possible, if not use it anyway as it could save lives.
P401	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: I believe that screening should be recommended. This is because early detection of prostate cancer will have benefits, especially for those in the highest risk groups. Nationwide recommendations for prostate screening to those with a family history of prostate cancer is a step forward to improving the state of healthcare in the UK. Other comments: No

P402	Affected Comment: No. Evidence Comment: Prostate Cancer UK's projects include designing and leading Real-World Data studies to fulfil evidence gaps in prostate cancer so the charity advances in their research. Discussion comment: We could find out the risk of getting cancer by studying those who are already at risk. Recommendation comment: Screening should be recommended to raise awareness about prostate cancer and how we can help to stop it. Alternatives comment: We could do a charity run or a cake sale to give money to those in need of treatment. Other comments: No
P403	Affected Comment: No Evidence Comment: No Discussion comment: I think you are doing a good job Recommendation comment: Yes because it is good to do just in case Alternatives comment: I don't know Other comments: No

P404	Affected Comment: Yes Recommendation comment: The case for routine PSA testing every two years is now overwhelming. Prostate cancer is one of the UK's most common and deadliest male cancers, yet early detection is being missed. PSA testing is simple, low-cost, and effective at identifying cancer at a stage when treatment saves lives and reduces long-term NHS burden. This is especially urgent for men of colour, particularly Black men, who face significantly higher incidence, earlier onset, and higher mortality from prostate cancer due to genetic risk factors. A passive "informed choice" approach is failing these communities. Equality in healthcare requires proportionate action, not equal neglect. Delaying structured PSA screening is not neutrality. It is a decision with predictable harm. The evidence base, the genetic risk, and the moral obligation all point the same way. Introduce biennial PSA screening. Save lives earlier. Act now! Other comments: The case for routine PSA testing every two years is now overwhelming. Prostate cancer is one of the UK's most common and deadliest male cancers, yet early detection is being missed. PSA testing is simple, low-cost, and effective at identifying cancer at a stage when treatment saves lives and reduces long-term NHS burden. This is especially urgent for men of colour, particularly Black men, who face significantly higher incidence, earlier onset, and higher mortality from prostate cancer due to genetic risk factors. A passive "informed choice" approach is failing these communities. Equality in healthcare requires proportionate action, not equal neglect. Delaying structured PSA screening is not neutrality. It is a decision with predictable harm. The evidence base, the genetic risk, and the moral obligation all point the same way. Introduce biennial PSA screening. Save lives earlier. Act now.

P405	Affected Comment: no Evidence Comment: no Discussion comment: no Recommendation comment: im not sure Alternatives comment: no idea Other comments: no
P406	Affected Comment: no Evidence Comment: no Discussion comment: no Recommendation comment: idk depends on severity

P407	Affected Comment: My father died of prostate cancer. Evidence Comment: The lack of screening undoubtedly played a part in far-too-late diagnosis. Discussion comment: As you certainly know prostate cancer is now the most common cancer in the country. I completely understand that there can be detrimental consequences to treatment. Though that is of course true of treatments for many cancers. There is a strong feeling that the failure to create a screening programme is sexist and ageist. Recommendation comment: Definitely. Actually not for myself... I'm just going to be a persistent 'pain' to my GP surgery! But the lack of a structured regular screening programme means more marginalised groups in society are excluded from potentially lifesaving treatment. I note that my recent ***** yr old Well Man assessment did not raise at all prostate issues... which seems a bit silly. Alternatives comment: I have no idea what the 'many alternatives' are. So can't comment. Indeed this question is surely flawed. The only rational answer is to catch the cancer early. Your question rather implies not addressing this crucial aspect and instead just managing 'the condition'. Seems something of a surrender. Other comments: I understand that there are negatives (sometimes) to dome treatments of prostate cancer. But essentially the argument then is... better not to know if you've got prostate cancer as treatments can be tricky. Surely 'ignorance is never bliss' when it comes to cancer. Identify a cancer in a patient and then help the patient weigh up pros and cons of treatment. Patient Autonomy rather than patient ignorance.

	The latter seems rather unprofessional.
P408	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: I don't know Alternatives comment: Make it more open to people Other comments: No

Affected Comment:

Mr brother was diagnosed with Prostate Cancer in *****, there was no family history. After medication, radiotherapy and chemo, he died in *****,.

His best friend was diagnosed some years later, again with no family history and following treatment he died in *****,.

My ***** was diagnosed following a company medical in *****,, with no family history he had surgery, followed by salvage radiotherapy but no drugs or hormones and, thankfully still records an untraceable PSA to this day.

A friend was diagnosed in *****,, no family history, his PSA was high had a brief course of radiotherapy but he died ***** later of COPD with Prostate Cancer the second condition on the Certificate

Another friend was diagnosed in *****,, no family history and following surgery is now under watchful surveillance with a PSA of *****,.

Evidence Comment:

Concerning 'evidence', I would say that all of the above men had no family history and that it was only ***** who had very minimal symptoms, the others had no symptoms at all with no reason to think anything was wrong and the possibility that Prostate Cancer would be present was only indicated by the PSA test which they had had as part of a General Medical or their wives nagging them. They all had but one had biopsies which confirmed it. The most recent had confirmation by MRI.

Discussion comment:

Women are routinely called for mammograms from the age of 50 and also for Cervical Cancer from (I think) the same age *****. The test for Cervical Cancer was, for me and many others excruciating and we would have welcomed the opportunity of a blood test to replace it.

The three men who died all had families and it is more than likely they would be here today had they been screened, I would suggest every two/three years from age 40. Much is made of the side effects of unnecessary treatment, as is also mentioned on the leaflet sent with the Mammography invitation. In my opinion which I have found when I used to go to my husband's Support Group, the fear of impotence seems to be high on the list of men's anxiety about the treatment of Prostate Cancer. My brother was terrified of this and I urged him to speak to his Oncologist and he got help to solve the problem. This fear, I am sure, causes men to agree that screening for the PSA test is not worth it. Ut fail to see that the value in getting a baseline figure IS worth just having a blood sample tested.

Recommendation comment:

At the moment the PSA test is all we have but how is it sensible to say that it is not worth having because it is not a

reliable indicator that Cancer is present? Statistics are excellent things for predicting things which can easily be analysed numerically. Human beings are not numbers and should not be treated as such. Just because a man has. no relatives who have had the disease exactly what does that 'prove'. Estimating the numbers likely to prove positive by their family history or

	background is equally unreliable. I would welcome being corrected but I don't think that Prostate Cancer was automatically recorded on Post Mortem results in the past, so, therefore, men over thwcage of 30 or 40 might have no idea that a relative had tbis. The only way to find out how many men have the potential of a diagnosis of Prostate Cancer is to do a mass testing of all men over 40 (or even) 30 and I am sure the results will be surprising. Alternatives comment: I do not understand the question. How else could you find the potential for the illness other than screening and if the men already have this condition, presumably they have been diagnosed? Other comments: Many men I have met (including my *****) have not had symptoms of Prostate Cancer or any history of it in their families. Those who have had relatives or friends die from Prostate Cancer do not wish to see more deaths which could have been prevented. It is not the voices of the statisticians that we should take heed of but those of people who mourn *****, sons, brothers or friends who, perhaps for the sake of a simple blood test, would be with them today. Maybe that will considered to be a simplistic or sentimental argument but, nevertheless it is true.
P410	Evidence Comment: TELL every GP across the country that if they are already asking for other routine blood tests for a man over 50, then a PST test is AUTOMATICALLY ADDED to the other requirements. (to be clear.. that's an instruction to GPs.. not an ask of GPs!) TELL all GPs that they CANNOT refuse a PST test if a man turns up in their surgery and is asking for it. Any request MUST be noted clearly on the patients health record. We all hear how difficult it is in many instances to get men into GP surgery's.. so at least when they do turn up – GPs must not add any barriers or make it more difficult etc. (again.. this is an instruction to GPs) Recommendation comment: AUTHORISE the immediate standing up the prostate cancer screening programme for men across the whole of the UK. This should be up and running no later than 1 April 2027. Yes that's, 2027.. it simply can't wait any longer ! Other comments: 1 – AUTHORISE the immediate standing up the prostate cancer screening programme for men across the whole of the UK. This should be up and running no later than 1 April 2027. Yes that's, 2027.. it simply can't wait any longer !

	In the interim, 2 – TELL every GP across the country that if they are already asking for other routine blood tests for a man over 50, then a PST test is AUTOMATICALLY ADDED to the other requirements. (to be clear.. that's an instruction to GPs.. not an ask of GPs!) 3 – TELL all GPs that they CANNOT refuse a PST test if a man turns up in their surgery and is asking for it. Any request MUST be noted clearly on the patients health record. We all hear how difficult it is in many instances to get men into GP surgery's.. so at least when they do turn up – GPs must not add any barriers or make it more difficult etc. (again.. this is an instruction to GPs) (.. a friend of mine was refused by one GP.. and then another GP in the same surgery agreed.. and then the result turned out to be outside of normal range ! Absolutely not acceptable.. ALL GPs MUST agree to ALL PSA tests first time round if asked for !.. No if..buts or daft excuses from GPs)
P411	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: No Alternatives comment: No Other comments: No

Affected Comment:

Dear NSC,

My father died of Prostate Cancer ["PC"]. Aware that those individuals with a family history of the disease face a significantly higher risk, I have – for somewhat selfish reasons – been particularly interested in seeing how I might reduce the risk of my ending up with PC!!

My doctor has kindly ensured I have a PSA test each year. He has told me that although not perfect, the PSA is a useful starting point for further treatment. He looks especially to see if there are significant variances in the annual PSA levels over a period of years. Apparently, the elevated PSA testing has got a lot more sophisticated recently, enabling a far more beneficial diagnostic pathway to take place rather than an immediate biopsy.

I have also participated in ***** trial – which is conducting further very useful research into the treatment of PC. I had a PSA test and then a MRI scan at *****, in *****. (Luckily I was told the PSA level and the size of the prostate showed I was ok.)

Recommendation comment:

I have no understanding whatsoever of things medical, so cannot speak with authority on this aspect. But I am aware that the UK NSC's draft recommendation suggests that only men with confirmed BRCA1 or BRCA2 gene variants every 2 years, from age 45 to age 61, should benefit from a screening programme and that the committee does:

- Not recommend Population Screening
- Not recommend targeted screening of Black Men
- Not recommend targeted screening of men with family history of the disease.

Apart from those with a family history of the disease, I believe black men also face a significantly higher risk.

I really would like NSC to support a National Screening Programme for all men above a particular age (?45), but if this is not possible at the moment, certainly for those with a family history of the disease and black men. The recent Lancet Commission on prostate cancer unequivocally emphasises the need to expand testing in high-risk groups.

Independent modelling for Prostate Cancer Research (PCR) shows a targeted programme would cost around £25m a year, just 0.01% of the NHS budget, and analysis for PCR by Deloitte UK shows a targeted programme would generate £54m in net socio-economic benefit, due to earlier treatment. That seems to me to be a strong indicator to support National Screening far beyond what NSC is currently recommending.

P415	Affected Comment: Not at all i dont think Recommendation comment: Yes because maybe it could help
P416	Affected Comment: Yes, my father was diagnosed at around *****, and chose to take hormone treatment only. I also was diagnosed in *****, initially opting for active surveillance, later moving to active treatment after a subsequent biopsy identified a high grade present, treatment plan was ***** with ***** followup. Evidence Comment: Yes. * There seems to be too much focus on temporary and/or physical harms without recognising either the temporal nature e.g most biopsy effects are psychological and temporary, and most serious physical effects are likely to arrive years into the future. Those that are more immediate, if they happen, e.g E.D or bowel/bladder control are not properly quantitatively or qualitatively risk assessed in particular engaging with potential patients to ask for views. * There was far too much focus on largely irrelevant assessment such as one-off tests and whole of population screening, which for any disease that has age progression as a factor in its genesis, would clearly limit any value. This was used as filler. * There was nothing to represent the benefit of a program likely producing improved diagnostics, treatments including reduced harmful effects, and the increased awareness, education and potential peer pressure from concerned friends and family NOT to 'die of ignorance' * I would challenge the assertion the majority of men would not benefit in terms of saving lives. It was stated that 76% (circa 9000 of 12000p.a)of men that die are older men. If these had been identified earlier through a screening program a large percentage of these would survive. The analysis is based on the CAP and CEASAR studies, which were not widely publicised, and ignored the effect of increased awareness, availability, education and peer pressure by friends and family not to 'die of ignorance' * 'Around three quarters (72%) of people with a raised PSA do not have prostate cancer',this number suggest the thresholds are wrong, or at the very least very least they should be adjusted to improve the confidence level. * It was stated 'assumed uptake of prostate cancer screening to be 36%'. No comparisons were made with initial take-up of other programs such as breast or cervical screening. I would have expected these other programs to be better, because historically women engage more with health care, a program would enable women to promote take-up as concerned partners. * The report makes significant use of the term 'over diagnosed' but equally fails to offer any way of qualitatively predictively identifying it, instead relying on assumptions, which if wrong affect real people, often causing death. * The WTP 'assumed' threshold seems miss guided, most men that can be saved will likely be identified in their 50's and 60's when they are at the peak of their earning capacity and by implication, paying the greatest taxes, if a man works even 5 Years longer due to successful treatment, that is not only cost neutral, it starts to fund the older non worker men's treatments * Going back to other specific programs, Breast screening- 1,300 deaths annually prevented (NHS) in 2007, 18 years after program a 36% reduction (BMJ), Cervical screening – 100-300 avoided deaths (prevention of ~70% deaths (PubMed), are mens lives less valuable ?

	Discussion comment: Yes. In summary, this report feels like it had decided on the recommendation, and spun the evidence and narrative to fit, without highlighting improvements that are likely in diagnostic tests, treatments and outcomes, awareness and education that would naturally be driven by a screening program. A last question, would you advocate an older person that is becoming forgetful to put it down to 'just getting older' or encourage them to be assessed for dementia? It seems similar, although dementia doesn't result in death. Recommendation comment: Targeted screening should be recommended for a number of reasons. * Deaths rate of prostate cancer is significantly higher than that for breast cancer and the deaths of men increases dramatically inline with age progression. We should be trying to reduce all deaths. * Death rate of men increase exponentially with age, probably related to an almost 50% initial diagnosis at stage 3 or 4, may of these could be caught at stage 1 or 2 with a program. * Prostate cancer has a fantastic survival rate which would only improve if occurrences were caught earlier at stage 1 or 2. * Men deserve equity of healthcare provision, especially when the economics would support it Stage 1 or 2 is cheaper to treat than stage 4. * Assess the improvements in other cancer screening and treatments post implementation. It is short sighted to delay any further. Alternatives comment: interesting question about alternatives, so why was none of them listed or referenced in the paper? While I acknowledge the scope was about screening, if would be somewhat disappointing of any credible alternatives were not even mentioned ? Other comments: I would like to suggest an immediate national PSA test program of targeted (50+) men and repeated screening be initiated to start the process of the improvements and benefits of participation, education, diagnostics and treatments, providing data for review in year 5 and 7 (if year 5 remained inconclusive). Given that the NHS guidelines already state any male over 50 can request a PSA test, it would provide the structure around what is already in place to guide the program to a better outcome. If the NHS wanted to be bold it could include the Galleri test as a double test even if for a limited time, with a view to PSA being replaced if results were to support it, possibly even looking to condense other screening programs into a Galeri based program for a wider population
P417	Affected Comment: no it has not that i know of. Evidence Comment: no Discussion comment: no

	Recommendation comment: no Alternatives comment: no Other comments: no
P418	Affected Comment: It hasn't that I know about Evidence Comment: I don't think so. Recommendation comment: Yes because cancer can become very dangerous if it isn't treated quickly and could lead to people losing their lives. Alternatives comment: I think if they don't already they could give vaccinations to protect you against the cancer and the government could pay the NHS more money so that they can have better and more accurate equipment for screening and also treatment.
P419	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: No Alternatives comment: No

	Other comments: No
P420	Affected Comment: No but I hope it stops. Evidence Comment: I would say no. Discussion comment: No I would say to not give up. Recommendation comment: I do not know Alternatives comment: I do not know Other comments: Keep going
P421	Affected Comment: no Evidence Comment: no Discussion comment: i hope prostate cancer someday receives a cure. it's a very serious disease and it has killed many. Recommendation comment:

	i think it should be recommended because it's a very serious matter. many people should know about it and how to identify it. Alternatives comment: releasing a public statement Other comments: not really.
P422	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: Yes Alternatives comment: By scanning early Other comments: No
P423	Affected Comment: My Prostate Cancer was diagnosed in *****. I receive a short course of hormone therapy followed by radiotherapy.I am monitored on a ***** monthly basis with further PSA tests. Discussion comment: I Recommendation comment: One PSA test is not conclusive. It may indicate a high but false reading or it may not record a reading at a level to, mistakenly, indicate a problem.

	Not only should there be screening. It should be carried out annually so as to create a pattern, which is how my diagnosis was reached. As Prostate cancer is now the most common cancer, it would be morally, even criminally, wrong to deny all men the chance of survival. At present the PSA test is the best method available. Until a more reliable test is developed, it should be freely available, not just on demand from Doctors who might even be sceptical – usually through ignorance.
P424	Affected Comment: yes, it affected my grandad Recommendation comment: it should be because it will help people catching cancer cancer early
P425	Affected Comment: I have had several colleagues die from prostate cancer and have friends and colleagues who have been diagnosed and treated. My best friend has a family history of pancreatic cancer and was treated in *****. Even though aged ***** and in good health I have a an annual PSA test at my local surgery and discuss the results with my GP Evidence Comment: While I welcome the UK NSC's draft recommendation to introduce targeted screening for men with BRCA1 or BRCA2 genetic variants, this proposal is fundamentally insufficient in its current scope. By excluding other high-risk groups and the general population, the committee continues to rely on a diagnostic paradigm—PSA and MRI—that is known to be limited, while seemingly ignoring emerging epigenetic technologies that resolve the very “harm vs. benefit” concerns cited by the committee. Discussion comment: The UK NSC's current model justifies the exclusion of wider screening based on an estimated 40% to 50% over diagnosis rate when using standard PSA testing. While I acknowledge the importance of avoiding over treatment, the committee's reliance on historical data from less accurate tests creates a circular logic: screening is rejected because tests are inaccurate, yet modern, highly accurate tests are not integrated into With approximately 12,200 men dying annually in the UK from prostate cancer, the current “wait and see” approach is not a neutral position—it is a decision to permit thousands of preventable deaths.

	The committee's current modelling emphasizes the side effects of biopsies (e.g., infection, erectile dysfunction) without adequately weighing the 94.2% ten-year survival rate for early-stage diagnosis versus the significantly lower survival for late-stage, metastatic disease. Recommendation comment: The UK NSC's draft recommendation for BRCA1/2 carriers is a small step, but it leaves the vast majority of UK men at risk. Prostate cancer mortality is projected to rise to 17,500 deaths per year by 2040 if diagnostic strategies remain stagnant. We cannot afford to wait for the conclusion of decade-long trials (TRANSFORM) while ignoring proven epigenetic tools available today. Until a national screening programme utilizing high-specificity tests like EpiSwitch PSE is developed, thousands of men will continue to die unnecessarily. The current "benefit vs. harm" calculation is weighted against the patient; it is time the UK NSC aligns its recommendations with 21st-century genomic science. Other comments: The UK NSC has pinned its future strategy on the TRANSFORM trial, which still utilizes PSA as a primary screen. This is inherently flawed: PSA has a predictive accuracy of only approximately 55%, leading to nearly 75% of patients with elevated levels undergoing unnecessary follow-ups for non-malignant conditions like BPH or recent exercise. While multi-parametric MRI (mp-MRI) improves specificity, it is expensive, subject to interpretation variability (PI-RADS scores), and is contraindicated for many patients, such as those with cardiac pacemakers. The committee's evidence review appears to have overlooked the EpiSwitch PSE (Prostate Screening EpiSwitch) blood test, despite its published real-world clinical utility (Berghausen et al., 2025). The PSE test directly addresses the committee's concerns regarding over diagnosis and biopsy harm: The PSE test combines PSA with 3D genomic markers to achieve a 94% accuracy and a 97% specificity. In real-world studies, the PSE test allowed up to 79.1% of patients to safely defer or avoid unnecessary invasive biopsies. The test demonstrates a high negative predictive value, functioning as a reliable "rule-out" tool that could reduce the demand for NHS MRIs by over 86%.

P426	Affected Comment: no Evidence Comment: nope Discussion comment: Dont think so Recommendation comment: yes because help capture cancer early Alternatives comment: dont know Other comments: no
P427	Affected Comment: no
P428	Affected Comment: I had my prostate removed in ***** by open surgery. It has, of course, affected my life/lifestyle thereafter. I wear a pad every day. I have had erectile disfunction, ever since my prostatectomy. But – I am a very positive person, and get on with life. People have all sorts of ailments and have to live with them. It is nearly ***** years since my operation, and I'm still here, living a good life. I don't feel as though my family has suffered. Certainly my friends have not. Evidence Comment: I don't doubt the evidence considered in the review. Discussion comment:

	Yes. I am completely against the recommendation in the review. Deaths from prostate cancer are huge (50 to 60 thousand diagnosis per year) and yet the committee concerns relate more to fears/worries relating to individuals and their families, incorrect diagnosis, Well, I can tell you that from a personal viewpoint, I would prefer to know if something is not quite right, cancer or no cancer, and to go through any psychological issues rather than being told 6 months later I have prostate cancer, with about 9 months to live. I am a ***** of a prostate support group ***** , and in the last ***** years the group has tested over ***** men, many of whom are only alive today, thanks to having a PSA test, some of which were turned down by their local GP. Recommendation comment: There may be question marks on the accuracy of the PSA test, but its all there is at the moment. It may not be totally reliable, but it at least suggests that something is not quite right 'down below', and some investigation may be needed. What else is there? The death rate is absolutely shocking, and if the proposed PSA test screening program is declined, the deaths will continue/increase, leaving men more worried than ever, particularly so when their GP refuses to provide one. I am absolutely 100% for a screening programme.
P429	Affected Comment: Yes. I was diagnosed with Prostate Cancer in *****. Discussion comment: Insufficient weight was given in the review to the benefits of monitoring trends in PSA readings over time (even in the absence of physical symptoms) and referring patients for further tests when an upward trend is detected. Recommendation comment: Yes. In the absence of physical symptoms regular PSA screening (e.g. annually) can reveal a trend of rising PSA levels which would warrant further investigation or referral. This happened to me where a rising trend in annual PSAs over ***** years triggered a referral, further tests, and a Prostate Cancer diagnosis (*****). Following a prostatectomy ***** years ago I am now cancer free. I am convinced annual PSA tests saved my life. Alternatives comment: Whilst not 100% reliable PSA screening is currently the only available non- invasive means of detecting Prostate Cancer. A simple finger-prick test offers a potentially easier and more cost effective method than a conventional blood test which should save costs for the NHS. Follow-up Digital Rectal Examination and/or MRI scans would minimise the need for follow-up invasive biopsies where the risk of cancer is considered low.

P430	Affected Comment: Yes. My father was diagnosed with it and had hormone treatment for many years until it spread to his spine before he died. The regular visits to his NHS consultant to monitor the effectiveness of the hormone treatment were reported back with enthusiasm. My own experience is that a 2 yearly PSA test is a reassurance that such a condition/pathway is not inevitable. To deprive the majority of the male population because of the potential harm that future testing/treatment may cause seems perverse. I would prefer to know and be given a choice. Evidence Comment: no Discussion comment: At ***** I still believe I should be offered a PSA test or alternative – it should not be down to me to request it from an already stretched GP practice. Prevention must be better than cure. Recommendation comment: see above Alternatives comment: I don't see what the alternatives to screening are. Other comments: Clarify what age limits are being placed on the screening that is available through the NHS.
P431	Recommendation comment: No i dont think you should beacuse we are young we dont have the chance of catching it
P432	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: Yes

P433	Affected Comment: I'm an NHS GP who has treated hundreds of men with prostate cancer. I've had several friends and family with this condition, including some who have died. I'm a ***** man who stands to benefit or be harmed by any potential screening programme. Evidence Comment: This was an incredibly thorough review with no obvious omissions. I applaud the work of the NSC. Discussion comment: I consider the report to be well balanced and I support its recommendations entirely. Recommendation comment: No. The evidence suggests it would probably do more harm than good. Alternatives comment: By providing realistic and effective treatment, as is currently the case, and continuing to support research. Other comments: Decisions about screening programmes should be made by experts on the basis of evidence, Not by politicians, not by the Telegraph campaigning for a screening programme that they don't even know the shape of. I'm not even convinced this public consultation is of value. Very few of the responses will add anything valuable and scientifically valid to the painstaking year's work by the NSC. Well done NSC.
P434	Affected Comment: Not directly but a lot of Family friend's families and distant relatives have been affected Recommendation comment: Should as its so much better to be safe than sorry and save more lovely people such an awful fate

P435	Affected Comment: Every man who has symptoms related to the prostate must have screening, regardless the age. Evidence Comment: N/A Discussion comment: No Recommendation comment: Should be recommended. If detected early better for treatment Alternatives comment: I don't think only blood test is enough. Sometimes needs more investigation.NHS- more appointments available Other comments: Better early than later
P436	Affected Comment: it hasnt affected anyone in my family nor i (to my knowledge) Evidence Comment: no Discussion comment: no Recommendation comment: yes because cancer can hypothetically be detected early and that would be good Alternatives comment: maybe encourage people to do monthly checkups and if they have cancer, they can remove it in time Other comments: no

P437	Affected Comment: No. Evidence Comment: No. Discussion comment: No. Recommendation comment: I think it should be because apart from some false answers, the test can help many men in supporting a happy, healthy life.
P438	Affected Comment: I go to ***** School in *****. There is a lot of boys in my school who have family who are affected by prostate cancer. Evidence Comment: Make sure men are spoken to. Recommendation comment: Screening should not be taken place. Alternatives comment: Give them extra support as men don't usually talk about there problems. Other comments: Don't do screening
P439	Affected Comment: No Evidence Comment: No Discussion comment: No

	Recommendation comment: Should not as it might hurt really bad Alternatives comment: Warn people about it Other comments: No
P440	Affected Comment: no Evidence Comment: no Discussion comment: no Recommendation comment: yes Alternatives comment: not sure Other comments: no
P441	Affected Comment: My father had this cancer. He had his treatment and recovered Evidence Comment: I feel that maybe need a bigger test group to get more Range on the results Discussion comment: Feel let down as I in high risk group and there seem no planing for us just leftin limbo Recommendation comment:

	feel that maybe a targeted testing programme needs to be considered as there are high risk groups who might be much more suited the testing Alternatives comment: Target people of high risk with e mail and text messaging to remind of risks and what to look for
P442	Affected Comment: No
P443	Other comments: Nope
P444	Affected Comment: mate I'm just worried of getting cancer and dying Recommendation comment: well it should because I believe it will help people
P445	Affected Comment: no Evidence Comment: no Discussion comment: no Recommendation comment: should for schools since teachers use it to help us learn Alternatives comment: i dont know

	Other comments: no
P446	Affected Comment: No
P447	Affected Comment: nah not really. Evidence Comment: im not too sure about that tbh. Discussion comment: dont think so no. Recommendation comment: i think you should do whatever you want. Alternatives comment: not sure. f f f f f f f f Other comments: no.

P448	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: No Alternatives comment: Fund it more Other comments: No
P449	Affected Comment: No Evidence Comment: No Discussion comment: No Recommendation comment: Yea Alternatives comment: Idk Other comments: No

P450	Affected Comment: N/A Evidence Comment: N/A Discussion comment: N/A Recommendation comment: N/A Alternatives comment: N/A Other comments: N/A
P451	Recommendation comment: I think it should to help stop cancer in young people
P452	Affected Comment: ***** years ago I had Prostate Cancer. The only symptoms were secondaries on my spine giving me intense back pain. Only this led to a PSA test. I had zero effects from the Primary cancer (no peeing in the night no discomfort) yet I had a PSA of *****. If there had been a screening process I am sure the cancer would have been discovered earlier. My GP merely explained to me why I should not have a PSA test. Evidence Comment: The existence of completely symptom free Prostate Cancer means that the only way to stop it killing people like me is to have a regular screening process. Discussion comment: It is ludicrous to limit the screening to BRACA men as most of them will be unaware that they have the subset.

	I may have it but still have no idea as I have never had such a test. Recommendation comment: It MUST be introduced to save people like me who have symptom free Prostate Cancer. The argument against is not that the PSA is dangerous. It is that the next stage – each authorised by a medical professional is dangerous. To not do the PSA to save the Doctor from a potential mistake in authorising a secondary dangerous procedure is clearly ludicrous. Alternatives comment: There is no alternative to screening to find the symptom free cancer from which I suffered. Other comments: Lay down proper standards for the referral to biopsy or secondary diagnosis. This should look at sequential monitoring of PSA and only act if the PSA is increasing over some months, or is over a set number. (My ***** score should probably lead to an automatic biopsy) This is the way to save Doctors from ordering 'undesirable' biopsies.
P453	Affected Comment: My husband has been diagnosed with aggressive locally advanced prostate cancer at *****, his father had recently been diagnosed and treated which led him to monitor for potential symptoms. His grandfather died of prostate cancer. For the sake of my son and other generations in our family and others please consider a more robust approach to screening those most at risk. Recommendation comment: Should – reasons as above Alternatives comment: Better signposting of risk from 45 in cases with family history Education at schools / universities
P454	Affected Comment: My Dad sadly died from Prostate cancer and also another close family friend.
P455	Prostate Cancer

P456	Affected Comment: My husband is ***** and was diagnosed with high- to intermediate-risk prostate cancer at the age of *****. His cancer was detected through a private blood test that we chose to pay for ourselves. He was completely asymptomatic at the time. This information was then shared with the NHS, and following further investigations and tests, he is now undergoing a radical prostatectomy. This diagnosis came from what feels like a silver lining, we took our health into our own hands, and that decision may have been life-saving. Without that private test, his cancer may have gone undetected for much longer. His experience highlights a critical gap in current policy. Risk-based approaches to screening often focus on narrow or “obvious” categories, which can lead to younger men or those outside traditional high-risk groups being overlooked or dismissed. Prostate cancer does not always follow textbook rules. Policymakers need to adopt a more inclusive and forward-thinking approach to early detection, one that recognises emerging evidence, ethnic variation, family history, and individual concern, rather than relying solely on age thresholds or rigid risk labels. Early diagnosis saves lives, but only if access to testing reflects the real diversity of risk in the population
P457	Affected Comment: I have an uncle who has prostate cancer that is well controlled. A friend's father died at the age of ***** from prostate cancer. Evidence Comment: No concerns, the UK NSC has reviewed the appropriate evidence. Discussion comment: I agree with the review and it's recommendations. Recommendation comment: No, screening should not be recommended. I fully agree with the science and opinion of the National Screening Committee. I believe in science. The word science comes from the Latin word 'scire' which means 'to know'. Science is about the collection and interpretation of data in a dispassionate and unemotional way. We should not be listening to appeals to emotion from celebrities and charities. If you or a close family member has died from prostate cancer this is obviously very sad, but it shouldn't mean that we start a screening programme if the evidence does not support this. Alternatives comment: I think the British general public should be encouraged to seek private options if they are unhappy with what they get for free from the NHS. The NHS should provide evidence-based care only. For example, a private PSA test costs £30-£70 so people who are trying to overrule

	the NSC should just pay for a test. People can also pay for BRCA1/BRCA2 tests; I paid for 23andme in ***** so I know I am BRCA1/BRCA2 negative. Other comments: Honestly I think Prostate Cancer UK should be investigated by the Charity Commission for undermining public trust in our institutions. The NSC are genuine experts and Prostate Cancer UK has a financial interest in whipping up hysteria and feelings regarding this issue. The language they use on their website includes statements like 'The NHS is failing black men' which is wholly incorrect and inappropriate. They also want screening for black men, which is frankly racist. Many cancers have a higher incident rate in white people; bowel and bladder cancers are around twice as common in white people but we would never suggest that we should screen white people only or undertake research into screening for white people.
P458	Affected Comment: As a BRCA2 carrier, I currently undergo annual screening as advised by my regional genetics centre. I am concerned that if this is extended to 2 years this will put me at increased risk of a delay in diagnosis. Evidence Comment: Why annual screening shouldn't be continued. I don't believe this was considered or modelled in the papers Recommendation comment: Yes it should be recommended and also extended for those with a strong family history or ethnicity that puts them at increased risk Alternatives comment: Helping after the event is all well and good- the government has pledged to increase early diagnosis

Affected Comment:

I have been on active surveillance for prostate cancer for nearly ***** years now. As time went by I have become mostly at ease with my condition. In the early stages there was much apprehension and concern that some action should be taken. Anxiety rises as each six monthly PSA test becomes due. The main concern now is for my sons as they are at greater risk.

Joining local support groups helps and makes me realise how fortunate I am compared to many that have either had a terminal diagnosis, or living with the after effects of treatment. Giving support to those recently placed on active surveillance is equally beneficial to them and myself.

Evidence Comment:

In all the statistical evidence of how many trials and outcomes it seems to fail to account of the high morbidity rate of over twelve thousand deaths a year due to prostate cancer (greater than that of breast cancer). There is only one statistic that really counts 12,000 + deaths per annum from prostate cancer.

The lack of concern for the death rate over cost comes across as callous. That to some extent is tempered with the valid concern about unnecessary treatment. However not having a clear vision of how to address what is an alarming and unacceptable mortality rate smacks of just sitting on hands when it comes to the vote. What is clear is that until something better comes along early diagnosis (PSA testing) is the only credible answer to addressing the problem.

Discussion comment:

My understanding is that those who have BRACA 1/2 gene and those with a family history of prostate/breast/ovarian cancers are of greater risk and therefore would be targeted for screening.

I wonder how many of that cohort are unaware of having BRACA 1/2 genes. Those who don't know their biological family history – perhaps they were adopted or father was unknown, or was a sperm donor, etc. It seems you would only know if you had that gene would be by some unfortunate chance.

Recommendation comment:

If Prostate screening is not going to be routinely offered, I would be happier if there was routine screening for the BRACA 1/2 gene, and then those identified, plus other high risk groups are targeted for prostate screening.

In general the short answer is yes. Routine testing for breast, bowel, and cervical cancers all are done for a good reason – it saves lives. Testing for prostate cancer should be no exception.

Alternatives comment:

I don't believe there are plausible alternatives to screening. Not if you really want to get the 12K+ per annum morbidity rate down.

To save the expense and heartache of unnecessary treatment, together with the ongoing support that is so often needed afterwards, then better risk assessment of the condition to

	encourage more men to take the active surveillance option is required. This would be paramount if routine screening was introduced. Other comments: I am aware that alternatives to the PSA test are being developed, such as the SPIT and PUR tests which potentially will be able to discern between low risk and aggressive prostate cancer, and no doubt many others are also being developed, Better funding of these tests would hasten their conclusion. Development is often delayed whilst further funding is sought. Look how quickly the Covid test kits and vaccines were developed when adequate funding was made available! In my opinion for far too long the debate on prostate screening has been the procrastination about screening! GET A MOVE ON.
P460	Affected Comment: I was diagnosed with Prostate cancer in *****, purely by chance during a routine set of blood tests where I requested a PSA check. I suffered some nerve damage during the removal of my prostate, which resulted in ED. I went on to have a penile implant in *****. Evidence Comment: My concern is that there will not be a facility for my son to get regular and early checks for this cancer. As I had prostate cancer and so did my brother, the consultant recommended that my son be tested from age 40. That is in *****years time! Discussion comment: Early testing will UNDOUBTEDLY save lives. It will surely also save money within the NHS by eliminating more intensive and expensive treatment at a later/terminal stage. It makes moral and economic sense! Recommendation comment:

	Yes it should. It would save lives and, ultimately, save money. Alternatives comment: As the disease is often present without any outward signs or symptoms, it is hard to see how successful any alternatives could be. For example, public awareness of the symptoms would only alert a small percentage to the problem. Other comments: The sooner a comprehensive screening programme is introduced the sooner lives will be saved and the sooner the savings from later stage treatments will be seen.
P461	Affected Comment: I was diagnosed with high grade, aggressive prostate cancer in *****, aged *****. I had no symptoms, no family history and do not carry the BRCA gene. Yet my biopsy results scored a ***** on the Gleason scale and I was very lucky it had not metastasized. In *****, a chance PSA blood test detected that I might have an issue. An MRI scan was equivocal. A further PSA blood test remained elevated at *****. I had to push my Urologist to take biopsies. Thank goodness I did. After undergoing surgery, I had my prostate removed *****. There are some repercussions of course, but I am so thankful to that PSA blood test for providing an essential clue, just in time. Thanks to the brilliant doctors, nurses and physios, I've made an excellent recovery which has been documented in the press – ***** Evidence Comment: No, as I am not close enough to the science of evidence gathering. Discussion comment: Yes. How many men know if they carry the BRCA gene or not? My guess is virtually zero. I only know i don't carry it because I spent ***** following my surgery, getting a full panel of genetic tests at the *****. This was a significant expense but I wanted peace of mind for my son and brother. Limiting screening to men carrying the BRCA gene seems completely unworkable – it is just a nod to including a risk group. A tiny percentage of men know if they carry this gene mutation or not, and it would cost significantly more than a PSA blood test to screen for this mutation. Recommendation comment:

Screening should be recommended, at minimum, for black men over 45 and any man over 50 with a family history.

Alternatives comment:

Put screening into the hands of men over 45. If they proactively go to their GP to get a PSA blood test, they should be given one there and then. Too many GPs push back and make it so difficult for men to get a test, as their knowledge is stuck on outdated NICE guidelines. Retrain the GPs so they are aware of the interim steps between PSA test and biopsy (eg MRI or further PSA monitoring) and let men over 45 choose if they want a test or not.

Other comments:

Always call it a PSA blood test as most men still think PSA test means “finger up the bum” (DRE).

This is one of the biggest barriers to break down through education and awareness. Then, get behind the PSA blood test as a screening tool for:

- 1) black men over 45
- 2) any men over 50 with family history
- 3) any men who proactively ask their GP for a test

P462	Affected Comment: My husband was diagnosed with Advanced Metastatic Prostate Cancer *****. This was after a missed raised PSA test by a hospital department (a test completed unknown to my husband) in *****. A consultation with GP where he was counselled as to why it may not be the right thing to have a PSA due to negative results and unnecessary and invasive testing. Luckily, he still wished to have the PSA test which shown him to have ***** the most aggressive form of PC, with Cribriform and perineal invasion and spread to seminal vesicles and his neck, spine, 2 opposite ribs and pelvic area. His only form of treatment due to spread and other health conditions is Hormone Therapy. Prostag and Darolutamide. No radiotherapy, no chemotherapy. A life of hoping and praying the medication works but we have been told there is no way on knowing if it will work for months or years and in the meantime he is suffering with all sorts of additional serious health problems. It's too early to judge how this will impact at the moment. Had he decided not to take the test, despite telling the GP his symptoms in addition to the missed test by a ***** I dread to think where we would be in the very near future, as his cancer is very aggressive and fast spreading. My husband's father died when he was ***** and my husband was *****. There were no siblings nor other male members of the family so no family history. However, my husbands case is concerning and I felt the screening criteria is too small. It should include relatives of those with the highest Gleason scores at the very least and ideally any male whose relative has had PC where treatment has been received. Men deserve the same equality as women, funding and staff need putting in place. Education regarding the PSA test and what activities can impact on results and what to avoid shortly prior to testing may help. Had my husband had his test (or test taken without his knowledge actioned upon) earlier in life we wouldn't be in the dreadful situation we are now in. The impact on my husband isn't just his physical and mental health, it is mine too and our son and daughters and wider family. My son has been told by the hospital to get tested from the age of 40 now because of the aggressive nature of his fathers PC. Additionally the cost of all the testing, scans, Human Resources and medication at this very late Stage would surely have been far less costly to the NHS had his cancer been discovered at an earlier stage. Please reconsider giving men a cheap PSA test to save lives, be more cost effective for the NHS in the long run and most importantly to save lives. Evidence Comment: I am unsure of what evidence they have undertaken to come to this serious decision or what other options they have considered. They seem to have narrowed the criteria by not allowing men with family history to be screened automatically if I am correct, which is totally wrong. When my husband discovered his PC Gleason ***** and asked about Gene testing he was told no. How therefore can our son be expected to know he will definitely be allowed a PSA test in the future. My biggest fear is that this decision has been made not on the equality of men, nor the fact it is the biggest male cancer and the number of men that are dying with it each year but a financial decision. Not enough staff in the NHS to deal with the growing awareness of men, who are being educated about their health and wishing a PSA test. Some will just want a test without

symptoms, some will already have major symptoms, as my husband did but still had to spend 10 mins being counselled about the negatives of a PSA. It is apparent now that resources are being stretched as the awareness grows and I believe this has been the factor in their screening criteria.

Discussion comment:

I would like to have seen more publication about the review, more awareness and (if there was any we didn't see it) some patient input before they came to their conclusions

What was the reason they narrowed the criteria, how do they expect those with genetic factors to know when men who have been diagnosed are being refused genetic testing?

What evidence did they use and who exactly came to the final conclusions and what was there expertise?

Was there any meaningful discussion with Prostate Cancer UK?

Was there any meaningful discussion with prominent cancer sufferers such as Sir Chris Hoy, Stephen Fry to name but two?

What research into costings for early PSA tests as opposed to men having tests after many symptoms have been noticed and how this impacts on the NHS.

What about costings for Mental Health issues once a Stage 4 diagnosis has been received on patients and close family. Prostate Cancer is a male cancer but it is suffered greatly by wives/partners and family members because of many families such as ours it now feels like Russian roulette and we have that hanging over us, together with the debilitating effect of the hormone treatment in addition to the cancer itself and all that brings.

Recommendation comment:

Yes, I firmly believe it should be recommend for all the reasons listed above.

If it is deemed too expensive to offer to every man then the criteria needs widening because on this recommendation a lot of men will be missed.

I personally think it should be offered to all men but some additional education about the test, what a raised result may mean and what might happen afterwards. It would also be helpful that men knew what to avoid shortly before a PSA test so to avoid false positives.

Prostate Cancer is a killer, often silent until symptoms and then it can be too late.

Nobody refuses women breast screening nor cervical screening due to false results. Men should have the same equality given to them and this is me speaking as a wife and mother of a son who may now go on to have a serious form of this cancer because of the family history. It must feel like a ticking time bomb to him and both my husband and myself are devastated. If we knew at least he could get regular screening without having to fight for it, well at least that would be something.

Alternatives comment:

What alternatives?

If there are why aren't they being used already?

	The condition as you choose to label this cancer can only be found by PSA testing initially. If there was an alternative I think it would have been suggested. A blood test is the cheapest option I am sure, cheaper than an MRI. Education is a key factor to men and all those with an interest in Prostate Cancer. Once you are diagnosed with cancer then of course we need more specialists such as oncologists, oncology specialist nurses, hubs within hospital for MacMillan nurses and faster delivery of results because the waiting times between MRI, Biopsy, bone scan and CT scan are torturous. My husbands PSA testing initially via the GP was *****. He discovered he had ***** after his biopsy at ***** and then have to wait until ***** before any treatment began (other than the Bicalutamide to stop a flare, that was *****). That is a tortuously long time when you have been diagnosed with ***** and you know it's an aggressive form with other factors too. Other comments: More education for the general public More education for GPs about men who present with significant symptoms, they should not be given the option of choosing a PSA (if someone came with serious heart symptoms they wouldn't be choosing to opt out of testing for that so why Prostate Cancer, the biggest male cancer and kills thousands every year). More support available during the testing period. The mental health strain was enormous but there was no one to turn to. It was either a 2 day week Urology Specialist Nurse (not oncology) who to be honest was overworked and had 15 mins allocated time to tell you you had a serious cancer and answer questions. It felt impersonal, lacking support and at times frustrating because we were given incorrect information. We saw the Urology consultant once, at the beginning when the GP referred. That was for a DRE and flow test. We've never seen him since. I chased for the Urology appointment and things seem better there and we have had two informative meetings since *****. They are all still very busy but the atmosphere is better and the staff more empathetic. So perhaps staff training on how to deal with patients who have received the most devastating diagnosis and can't even get a prognosis because it's a guessing game.
P463	Affected Comment: Not applicable Evidence Comment: Not applicable Discussion comment: Na Recommendation comment: No

	Alternatives comment: Na Other comments: Na
P464	Affected Comment: Grandad had cancer test biopsy but was all clear Evidence Comment: No Recommendation comment: It should be recommended as cancer found early can be successfully treated but if it is found later it could be fatal or could cost the NHS more Alternatives comment: i believe screening is the only way to successfully find cancer at the moment. Other comments: no i do not
P465	Affected Comment: No however you never know if or when any of us could get it. Recommendation comment: I think screening should be recommended as it will help to detect any early signs of it which really could even save people's lives but doing the tests in a way which won't cause issues if you do not already have it. Alternatives comment: Treat them as best as possible.

P466	Affected Comment: My husband, ***** brothers in law and my father. I also have ***** sons who I am very concerned about.the Evidence Comment: The implication seems to be that it's an immediate move from a raised PSA to radical treatment. This is not true. My husband had no symptoms and it was both of his brothers being diagnosed that alerted us to a potential problem. Following the raised PSA he had an MRI, a biopsy and a PET scan before the decision was made to treat. The study seems to have ignored increasing anecdotal evidence that younger men with no symptoms are being diagnosed with prostate cancer. It is better to screen and treat early when needed than leave it too late. Discussion comment: I think the recommendation is flawed. There is evidence that prostate cancer is becoming more common and in younger symptomless men. The recommendation must be amended to include those, like my sons, who have a clear family history of prostate cancer not just those with the BRCA gene. Recommendation comment: I absolutely believe screening should be offered. There is national screening for bowel and breast cancer. There has to be screening for the, now, most common cancer. Alternatives comment: The treatment our family members received was excellent. The NHS is clearly able to manage treatment and recovery. This doesn't remove the need for an early screening. A simple blood test is an easy thing to do and is relatively inexpensive. Other comments: Yes, rethink your conclusion to include, at the very least, those with family history of prostate cancer.
P467	Affected Comment: After being refused a PSA test by my GP, I attended a charity testing session in ***** despite never having any symptoms. I was very surprised when I received the results a few days later that my PSA was *****. I was then retested by my GP and found to have a similar PSA of ***** , and I was then referred to the local hospital. After an MRI scan and biopsy, I was found to have cancer in the prostate and surrounding lymph glands. I then underwent ***** months of hormone treatment before a radical prostatectomy in *****. I would rather have an unnecessary scan and biopsy and find that my prostate was benign, instead of no PSA test and risk the cancer not being detected at an early stage.

	It seems crazy not to offer PSA testing to all men over 50, as my consultant says that every man over 40 has some form of prostate cancer, and it develops or not, from this age. Women are routinely screened for breast cancer, so why can't men be similarly screened for prostate cancer? Evidence Comment: Figures from PSA charities were not taken into account. Of 340 men who received a high PSA test, 95 were found to have the cancer Discussion comment: It seems crazy to only test women for breast and cervical cancer and not men for Prostate cancer Recommendation comment: Screening should be recommended for all men over 50, and particularly with those with a family history or men from nations with a predisposition.
P468	Affected Comment: na Evidence Comment: na Discussion comment: na Recommendation comment: yea Alternatives comment: idk Other comments: na

P469	Affected Comment: This has affected me personally. Thanks for a PSA test which led to scans, biopsies and the ultimate removal of my prostate. Had I not gone for a blood test this would not have been discovered and I am in full favour of early blood tests for men over the age of 55. Evidence Comment: Important to note that not generally screening is unhelpful. Discussion comment: Recommend early screening – PSA blood tests for all men over the age of 55 Recommendation comment: Should be because of my own experience Alternatives comment: Get all men over 55 a PSA blood test
P470	Affected Comment: I was diagnosed with Prostate Cancer as part of my ***** Health MOT through the NHS where my PSA was slightly raised. I had no symptoms, and a lot of my friends have not been invited to the health MOT. I have hopefully caught it early, had a radical prostaectomy ***** and am recovering well. I truly believe this has given me the best chance of survival and could easily have been picked up via a simple PSA test. I disagree with the 'false positive' argument, as there were several stages before I decided to have the op as well as speaking with my consultant I firmly believe that a national screening program would save countless lives and have no idea why it isn't already in place Discussion comment: There should be a screening program in place from 45 with the necessary support and guidelines as a minimum Recommendation comment: Definitely recommended, it may have saved my life and sure will apply to countless others

P471	Affected Comment: Yes~ several friends, some now deceased. Evidence Comment: My information is that the UK NSC recommendations were based upon outdated data and therefore that important evidence was missed. Discussion comment: Deeply Flawed. Recommendation comment: I recommend screening for all men over 60yrs. * The UK detection rate for PC is below the European average.* Over 12,000 men die of this complaint per year plus many others who suffer from long-term effects.* Mens health has long been rigorously ignored by the NHS, notwithstanding that men, via their taxes, are the biggest contributors to the NHS, and the people who use it the least. Alternatives comment: By discovering the condition as early as possible! Wider availability of new speedier MRI scans fro PC Other comments: NIHR funding for PC research should at least match that of the relevant PC charities. More, or 'smarter' use of, MRI scans for PC diagnosis.
P472	Affected Comment: My son has aggressive ***** prostate cancer. He was given a terminal diagnosis ***** years ago at age *****. Fortunately he was covered by private healthcare through his employment and was able to access swift expert care using MRI screening which gave prompt diagnosis, plus access to Abiraterone plus standard care. At the moment his cancer is under control. As a family we want all men from age 45 to have preventive screening through the NHS and access to the latest MRI screening rather than use of blood tests, and then swift diagnosis and access to the latest drugs.(see UCL Stampede 1 &2 and Transform clinical trials evidence). A proper screening programme using MRI and utilising AI will save lives, and save families from the pain of witnessing the early, avoidable deaths of their loved ones who will also leave behind a generation of fatherless children. Evidence Comment: They have not given sufficient weight to the latest research and efficacy of using high quality MRI scans and AI for early and comprehensive screening, which give far more accurate diagnosis and far fewer false positive findings.

	Discussion comment: The committee are missing a great opportunity to save lives by failing to recommended an effective screening programme that utilises the latest technology, and by only focusing on bracca gene carriers. Recommendation comment: Screening should be recommended for all men age 45 and over, every 3 years, to save lives and detect early stage prostate cancer. Alternatives comment: Raising awareness of prostate cancer warning symptoms should accompany a screening programme NOT replace a National and comprehensive service
P473	Affected Comment: I was lucky that I had a second opinion from my local GP who identified potential cancerous cells in my prostate which were cancerous. I believe I owe my life to this GP as early detection is key to a successful outcome. I think the committee have a prejudice against men as women get tested for breast cancer automatically (1 in 7 get breast cancer) White men (1 in 8 get prostate cancer) Black men (1 in 4 get prostate cancer) I would like this inequality looked at to save lives. Yours faithfully ***** Evidence Comment: Yes the ratio of men getting prostate cancer against women getting breast cancer Recommendation comment: Yes as stated in previous comments
P474	Affected Comment: Most of the men on my Fathers side of the family ha e been diagnosed with Prostate cancer My Father in law died ***** after fighting the disease for *****. Evidence Comment: Early diagnosis is key to beating this disease screening would help this to happen saving lives

P475	Affected Comment: Yes. I was diagnosed with this cancer in *****. This led to robot assisted prostatectomy which appears to have been successful. Evidence Comment: No. Discussion comment: Yes. I believe that the review has made a terrible error of judgement in not recommending screening. They have inappropriately shrouded their view with claims of evidence but actually it is not evidence led it is a values based position. They are saying that they believe its ok for some men's cancer to be missed even if these men die, in order to avoid some men having challenging remedial interventions. Recommendation comment: Screening should absolutely be recommended. Screening will save lives. I do not accept the argument that increased screening will result in "unnecessary" interventions. My experience tells me that PSA blood test, scans and, if there are concerns, a biopsy will give sufficient information on which to base a sound decision as to whether or not to "watch and wait" or to intervene. Alternatives comment: What alternatives? There are alternatives to radical interventions..but the alternative to a screening programme is no programme- what we have now and there are too many avoidable deaths. Other comments: There should be far more patient involvement in shaping the whilevpf yhe prostate cancer pathway.
P476	Affected Comment: I have stage 2 prostate cancer, picked up by a local charity screening program. Discussion comment: A cheap blood test,could say thousands of lives. Recommendation comment: It's a hidden killer,so why not screen. Other comments: Why do doctors ask why do you want a check,when all the adverts on the tv are saying, get yourself checked, is it down to funding at that particular doctors practice?

P477	Affected Comment: I have a close relative and a very good friend both currently undergoing treatment for prostate cancer, and had a friend pass away with(no symptoms) prostate cancer which had spread and became terminal. This is an insidious disease which has reached into many peoples lives and if we have the means to screen for it effectively then I can see no reason to fail to implement this policy Evidence Comment: I am not a clinician but feel that if the screening causes undue stress due to false positives it is small beer compared to the devastating effects of cancer Discussion comment: As above Recommendation comment: I believe that the screening programme should be recommended, however imperfect it may be, as the programme will encourage men to come forward for checking in a way that women now accept their breast and cervical checks Alternatives comment: I cannot think that there is a viable alternative to the screening programme as that is what we currently have and too many men are dying Other comments: Continue to research ways to make the screening process more accurate -the Nordic countries screening system seems to work according to a doctor who was at a Prostate outreach session I attended in Covid so why are we dithering
P478	Affected Comment: Please test ALL men over the age of 50. Evidence Comment: Please test ALL men over the age of 50. Discussion comment: Please test ALL men over the age of 50. Recommendation comment: Please test ALL men over the age of 50. Alternatives comment:

	Please test ALL men over the age of 50. Other comments: Please test ALL men over the age of 50.
P479	Affected Comment: My late husband survived for only ***** years after being diagnosed with Prostate Cancer with no symptoms which had already spread to his bones. He was ***** when he passed away. His consultant said this was an aggressive hereditary cancer which he had probably had for some time before diagnosis for which my son should have genetic testing. Recommendation comment: Screening should be offered for any man with family members who have had it without fighting for screening. My son has been refused a genetic test because the Dr maintains he is too young at *****.
P480	Affected Comment: Yes. My father had it and, at the end, it had spread to his bones. I have been under active surveillance for ***** years and, this ***** , have just been told that my Gleason is ***** and so I need to be treated. The cancer is contained inside the prostate capsule. I have been offered hormone/radiotherapy or prostatectomy. I am chasing HIFU as an alternative. I am not keen on hormone therapy so will plump for either of the other two... hopefully HIFU. Evidence Comment: No I am not qualified Discussion comment: No Recommendation comment: Screening is essential surely. It will save £millions in the long term and, more importantly, save lives. I keep thinking of Sir Chris Hoy in this regard.

P481	Affected Comment: Two friends were diagnosed with prostate cancer a few years ago, thankfully both have been treated successfully so far. This condition needs to be screened by the NHS. Recommendation comment: Of course it should be screened, early diagnosis is key.
P482	Affected Comment: Yes I have lost a relative to this horrible prostate cancer and a few of my friends. Evidence Comment: No Discussion comment: It definitely needs to be addressed Recommendation comment: Yes it has killed many men who had no symptoms before it's too late to be treated Alternatives comment: Compulsory for all men 50 or over every 3 years Other comments: Not at the moment
P483	Affected Comment: Yes. I was diagnosed with prostate cancer in ****. I had a prostatectomy in ****. Evidence Comment: Prostate cancer can exist without giving any symptoms. My symptoms were not those publicised as warnings. Discussion comment: Those with high risk should have opportunity for screening.

	Recommendation comment: Yes see above. Alternatives comment: More publicity of all possible symptoms. My urine flow was only effected after intercourse. Other comments: See above
P484	Affected Comment: My husband has advanced metastatic prostate cancer- advance. Because of *****. Our son is ***** and been refused a PSA test by his GP because he is not showing any symptoms. This is an appalling situation for us nut GP won't help because he is not compelled to give a PSA test Evidence Comment: They seem to have been guided by costs and overlooked the fact that earlier PSA tests will save the NHS huge amounts of money Discussion comment: Thank you for you hard work and efforts in supporting men and their families Recommendation comment: Absolutely- see earlier comments Alternatives comment: Staff training g and awareness that cancer can be advanced but no symptoms showing Other comments: Just easier access to PSA tests other than through GP Home testing if possible
P485	Affected Comment: Yes, two of my closest friends have had prostrate cancer. Both luckily caught it early and have had their prostrate removed and both are in their *****. I am in my ***** and have been diagnosed with an enlarged prostrate and rightly or wrongly suspect the worst is round the corner. I have luckily had my request for a yearly PSA test granted up to now.

	Evidence Comment: I believe the evidence considered was selective for the purpose of reaching the desired outcome. Discussion comment: They should be thorough detailed and not leave any stone unturned. They could also be verified before coming to a conclusion. Recommendation comment: Screenings should definitely be recommended due to the fact that like any cancer if caught early it is curable. Also this is something most men will unfortunately experience usually from the young age of 60.
P486	Recommendation comment: As a member of a higher risk group, I firmly believe that targeted or risk-based screening is a sensible first step, I deserve the opportunity of earlier assessment.
P487	Affected Comment: My younger brother was involved in a ***** accident in which he sustained a ***** on admission to hospital after screening for any other injuries they discovered he had prostate cancer luckily he has now recovered.Had it not been due to his accident we believe he would not be here today enjoying life where as a screening test would have been diagnosed earlier. Recommendation comment: I strongly believe screening should be recommended we get drummed into us that early diagnosis is a must in many medical cases.The frase,"Why change things that don't need fixing".THIS NEEDS MIXING" not in the future but NOW.
P488	Affected Comment: Yes diagnosed recently Evidence Comment: Its a grey area for people with the condition Discussion comment: It needs a national campaign tv advert Recommendation comment: Definately yes.

	I was diagnosed without knowing i had any problems Alternatives comment: More awareness of the condition Other comments: Make it a standard screening programme nationally
P489	Affected Comment: I have had a PSA tests which after an MIR and examination for possible prostate cancer it has now been confirmed as an enlarged prostate I have had to have a catheter fitted and I am awaiting an operation for my prostrate to be reduced The latest news for this is ***** to ***** weeks Evidence Comment: A PSA test with raised levels may not be prostate cancer but they indicate an issue which could result in some men being denied treatment before its too late Having no PSA testing is like saying that women should not have breast screening as the majority of them have no cancer when screened Discussion comment: With the figures being quoted of men dying of prostate cancer then the cost alone to the NHS would far out striped the cost of a quick blood test It seems to show that a programme of testing would be cost effective Recommendation comment: If a PSA test is quick and cost effective which could be carried out by a technician it would not put extra pressure on GPs or doctors if higher PSA levels are picked up then this could be monitored until the condition deteriorated eg further PSA tests showed that the levels had increased Alternatives comment: Screening is far the best way to pick things early as no other symptoms are always present to indicate that there may be a problem

	Otherwise making it easier to put out information such as signs of possible problems such as increasing amounts of going to the toilet at night etc Other comments: Increase funding to help come up with a more effective approach But at present PSA test is quick cheap and gives reassurance if nothing is wrong
P490	Affected Comment: The basic answer is yes it has. Anyone going through the treatments available is going to experience a life changing period of time. Recommendation comment: No. Alternatives comment: Once a year blood test available after the age of 40. Other comments: Introduce pop up blood test days at events like football matches and advertise the event prior to the game. Other events too like horse racing,cricket etc.

P491	Affected Comment: My father was diagnosed with PC in his 70's Evidence Comment: I believe that the evidence is disconnected from real life, and the harms of late diagnosis are underplayed, and the impact on high risk groups (black men) and inequalities is not fully recognised. Discussion comment: I'm of the opinion that the conclusions are overly cautious, and uncertainty is being used as a reason for inaction. Recommendation comment: Risk-based screening is a sensible first step, for men at higher risk who deserve earlier assessment and clearer pathways. While I understand concerns about overdiagnosis or overtreatment, I believe these can be managed in a modern health service. Alternatives comment: Organised prostate cancer testing instead of the current ad hoc system. Because of my father's diagnosis, I recognise the need to get myself checked annually, and each time I request a check up I am questioned as to why I need one. This is not good enough. There needs to be earlier risk assessment for higher risk men, clearer access to PSA testing, better GP support and education, improved public information, and action to tackle inequalities in access and outcomes. Other comments: Yes. Keep policy under active review as new evidence emerges rather than waiting every 2,3 or 5 years to re-review this. It is also important to involve patients and communities in future decisions. Further, while I understand that screening decisions are complex, lived experience should be considered alongside clinical evidence.
P492	Affected Comment: The condition affects myself. I have had a DNA analysis carried as part of the ***** carried out by *****. My DNA shows a mutation which results in a 1 in 3 chance of getting Prostate cancer and it being an aggressive cancer if I develop it. Recommendation comment:

	Screening should be offered. prostate cancer kills thousands of men every year. Because the disease can develop without any symptoms it is particularly important that screening be introduced urgently. Alternatives comment: A much greater awareness of the disease is developing, not least due to the very high profile campaigners who are promoting the very real problem. Many people are now using the NHS app, perhaps one suggestion could be to harness this and send notifications to all men over a certain age with guidance of symptoms etc.
P493	Affected Comment: A friend died with it and a family member
P494	Affected Comment: Hi I was diagnosed with prostate cancer ***** it was very difficult to deal with as I had no symptoms. After months of testing it was found that the tumour was protruding out the prostate and I recently had a prostatectomy. Evidence Comment: As I had no symptoms I was attending the doctors on an entirely different issue when a routine blood test showed a high psa level and through various tests and scans I had the diagnosis. Discussion comment: I feel very strongly that a national screening program should be available. After my diagnosis I have encouraged most of my friends to insist on a test. Recommendation comment: I can't believe we don't actually have screening already it's critical. Alternatives comment: I think that public information and awareness is key to an early diagnosis.
P495	Affected Comment: I am one of the lucky ones with a responsive GP and hospital. My condition was diagnosed & treated early with PSA and digital diagnosis. I have friends who were not and are no longer with us. The UK needs to be pro active with a screening programme.

	Discussion comment: A change in attitude is needed
P496	Affected Comment: As far as I know, it hasn't affected me or my family. I wouldn't know what I should be looking for though! Discussion comment: By providing guidance of symptoms, awareness would be raised and, hopefully, more individuals treated before a condition becomes serious. Recommendation comment: Yes, because I wouldn't know what I am looking for. Alternatives comment: Provide information on diet, exercise and general health that would treat the condition – if this affects it.
P497	Affected Comment: In my case, at the age of *****, I was symptom-free but a simple blood test led to the discovery of an early-stage but aggressive cancer. I believe I owe my wellbeing to the privately funded screening programme in which I took part, and the subsequent treatment from the NHS. Recommendation comment: Much has been written about the unreliability of the PSA blood test. In my case, at the age of *****, I was symptom-free but a simple blood test led to the discovery of an early-stage but aggressive cancer. I believe I owe my wellbeing to the privately funded screening programme in which I took part, and the subsequent treatment from the NHS.

P498	Affected Comment: Following postate removal the radio therapy the cancer had now spread to my bones. My family and I now look forward to hormone therapy and it's side effects for the rest of my life. Evidence Comment: I am a BRACA2 Gene carrier. This was only discovered following my daughter receiving breast cancer treatment and a ***** said she was a BRACA2 carrier and her family should be tested for the rogue gene. At the time I had no systems. However following MRI scans and a biopsy I was diagnosed with ***** postate cancer. Men are not born with a label attached saying BRACA gene carrier only screening will diagnose the problem early enough for the best treatment. Discussion comment: The only way forward is national screening. Not high risk patients only. How do you assess high risk? I had no symptoms only the advise of a highly respected Oncologist to get tested. Recommendation comment: YES. See my conclusions in the previous comments. Alternatives comment: No options or alternatives come to mind. Other comments: Start a national screening program immediately No time to waste. Why should men suffer the uncertainty any longer. I only found out by receiving advice from a Senior Oncologist.

Affected Comment:

I was diagnosed with prostate cancer *****, found only because I went to doctor for unrelated issue. I had ***** and he checked prostate as he was already doing an internal exam. If I hadn't had ***** it would not have been found. PSA test confirmed high reading subsequent mri biopsy found cancer had broken through the capsule. If it had not been found it would have spread. I am certain I would now be telling people I am terminal *****. Instead I am pleased to say radiotherapy and hormone treatment has brought my PSA levels back ***** and I can look forward to many years with my family and friends.

Evidence Comment:

I believe not enough evidence was gathered around men who have been or are going through their journey. Particularly around just how many are diagnosed not because of symptoms but as a secondary thought or a persons insistence for a PSA check. Almost everyone I have met in this past year going through treatment found out they had prostate cancer by accident. This is why screening is so vital as it sits in hiding with minimal if any symptoms. I have read how a false positive could be damaging for men's mental health. But I can categorically say if I had been told after my scan that I was ok and no cancer was found it would be pure relief and the angst while waiting on the results is the same whether you are found to have cancer or not. It should also be considered that every early detection improves the likelihood men survive this.

Discussion comment:

As above to much focus on mental health for those that have high PSA but then found to be cancer free, I think most would at the end of that process be delighted they are ok and for those that might have residual mental health concerns it's very simple to ensure support is available for them. Once a PSA is high the process for follow up is consistent with MRI and biopsy and depending on findings may also have a bone scan. All day to day simple procedures. To then give certainty on diagnosis which is all men want so that early detection gives better outcomes.

Recommendation comment:

We should definitely be screening. There are known higher risk groups, would be obvious to switch that on asap, from that you will see the data and can make known decisions as to whether a wider rollout should be done to all men over 55.

It would be so easy to run a pilot screening rather than a flat no, you need more actual data from real experience. A pilot would work and you could then set up the resources required to manage the increase in a defined area of the country. I believe the decision reached was in part due to the worry that nhs resources will not be able to cope with the increased demand due to higher number of genuinely positive cases. But why should it be different for this cancer compared to other cancers that do have screening programmes

Alternatives comment:

Pilot a screening programme in a defined geographic area and place the resources required to facilitate the programme early detection will cost nhs less than treating cancer that has further developed in people

Other comments:

	Only recommendation is listen to real people with real experience of the process and the current gaps in the decision making. It's is clear and obvious a screening programme will save lives and allow others to enjoy the outcome I have had. Without screening more people will die through Not knowing they have cancer in their prostate
P500	Affected Comment: Yes, I was diagnosed with prostate cancer in *****. This followed a psa test, and later confirmed through other scans, biopsies etc. Tge initial effect is devastating, with an internalised belief life is going to end soon. Particularly difficult to share with family, as my son is ***** , and without a full understanding of the implications. The support from nhs is mixed. ***** weekly phone calls are of essentially little use, as you are not listened to and questions are not answered. For example, I developed a shortness of breath, and the advice given was I could stop medication, as this was my choice. No alternative (reducing meds, other meds) was offered, no appointment offered, no alternative referrals considered. The negative effect on my mental and physical health was huge. Evidence Comment: The overwhelming view of people I know, medical professionals and lay people, is that early screening saves lives. If I had been screened earlier (I was diagnosed aged *****), my cancer could have have caught earlier, and treated sooner. Many others in ***** feel the same way. Discussion comment: The conclusions seem to be to be way too cautious, and do not reflect public concerns.

	While the psa test is not perfect, it seems cost is the determining factor, rather than the potential to save lives Recommendation comment: I have conceived the accuracy of psa tests, but from a cancer patient perspective, and with a ***** son aged *****, I'd like to believe he will be screened at as early an age as possible. No one wants men treated unnecessarily, but too many men die because the cancer is not caught early enough Alternatives comment: Clearer access to psa testing through an organised programme will save lives Other comments: Any good policy is kept under constant review, and not reviewed in a fixed multi year programme. In that way the public are kept inside with review updates based on scientific progress
P501	Affected Comment: I have a large prostate and have undergone precautionary tests. Evidence Comment: From a public perspective. I feel that the evidence feels disconnected from real life, and that the harms of late diagnosis are underplayed, and that the impact on high risk groups and inequalities are not fully recognised. Discussion comment: I feel the conclusions feel overly cautious, and uncertainty is being used as a reason for inaction, and that the discussion does not reflect the rising diagnoses, late stage presentations and inequalities. Recommendation comment: Targeted or risk-based screening is a sensible first step, as men at higher risk deserve earlier assessment and clearer pathways, and that while I understand concerns about overdiagnosis or overtreatment. I believe these can be managed in a modern health service. Alternatives comment: I feel that there's a need organised prostate cancer testing instead of the current ad hoc system, earlier risk assessment for higher risk men, clearer access to PSA testing, better GP support and education, improved public information, and action to tackle inequalities in access and outcomes. Other comments:

	The need to keep policy under active review as new evidence emerges rather than waiting every 2,3 or 5 years to re-review this, the importance of involving patients and communities in future decisions, and the need for urgency while remaining evidence led. A strong closing often focuses on human impact rather than technical detail. I feel its natural, that while screening decisions are complex, you want lived experience to be considered alongside clinical evidence.
P502	Affected Comment: I have recently undergone treatment for prostate cancer. I was fortunate in having an examination by my GP with PSA tests that picked up a sudden rise in PSA to me to admitted for scanning, biopsy followed by normal radiotherapy linked to hormone therapy, all this during Covid!! It was an acquaintance that suggested I go to see my GP after getting frequent poor sleep due to waking several times during the night. Best advice I'd ever had from a non family member! Evidence Comment: Not having read the evidence it seems to me that current access to diagnosis let alone treatment is a postcode lottery! Discussion comment: None as such Recommendation comment: Yes the sooner the better but also to include more prolonged post treatment monitoring given that PSA tests at present are considered too unreliable. I still worry my cancer could return! Alternatives comment: The NHS run routine promotion of breast & cervical screening for women, why not the same for Prostate Cancer. Other comments: Ultimately better blood screening & DNA mapping could perhaps help better determine familial risk and patterns amongst diverse communities alongside better education.

P503	Affected Comment: Grandfather died of Prostrate Cancer, father died of Prostrate Cancer and I have had my prostate removed after contracting Prostrate Cancer. Evidence Comment: None Discussion comment: Yes – the recommendation to not include screening based on family history is wrong. If I had not made my family history known to my doctor on a routine visit, he would not have tested me and my Prostrate Cancer would have gone undetected and I would now be dead! If I had been screened, then the disease would have been detected earlier and the treatment less invasive and expensive. Recommendation comment: Screening should absolutely be mandated for a strong family history of Prostrate Cancer and other cancers (e.g. breast cancer). Given this disease has taken my Grandfather, Father and was diagnosed in me, what % chance do you think it will manifest in my son? If I had not provided my family history to my doctor and he had not taken the decision to test me, I would now be dead. This should not be left to chance and screening should be mandated for family history markers. Alternatives comment: If screening is not to be mandated for family history then there should be a recommendation that all GP practises capture patient family history on prostate and other cancers and, those identified at greater risk due to family history, aligned to age, should be called forward for testing through the GP practice. This should also sweep up black men as an added risk factor.
P504	Affected Comment: My husband participated in ***** to look for something else but he was found to have BRCA 1 and 2 mutation. Our son and daughter also have BRCA2 mutation, a third sibling not tested. My husband never had prostate cancer but I feel as a woman we are offered breast and cervical cancer screening and prostate screening should be offered now to every high risk group urgently. I feel that men should be notified by the GP who is aware of the BRCA mutation and put forward for testing. Sadly at the NHS genetic testing my son was not really told much and not to worry as he didn't have children. A very wrong message to give. Surely with the gp txting system a prompt would be a good idea Recommendation comment: Yes it should even if it throws up false positives as do mammograms sometimes. Cheaper for the NHS in the long run

	Alternatives comment: They don't know they have the condition without screening
P505	Affected Comment: myself Evidence Comment: ***** years ago, aged *****, I had a full health check offered by my employer. During the health check I was asked if I would like a PSA test. I had no idea what this was but the doctor explained it to me. He said it was very unlikely to be an issue at my age. However, I said yes. The result was ***** and I had further checks by my GP, digital and PSA. I was told my prostate was small and smooth which indicated it seemed fine, however, my psa was gradually rising. A few months and tests later my GP referred me to the urologist at *****. Following a biopsy cancer cells were found. I was offered surgery at this time. After much research I joined a program run by *****. This was highly successful. I am still here ***** years later with a PSA of *****. The procedure was quick and easy and I have full function and bladder control. I am a white person of British heritage. It is essential that everyone is included in the screening program from a young age. Outcomes for men will be more successful and less life changing. Many lives will be saved. The cost to the NHS will be less. My treatment was a "day case". Surgery and ongoing treatment for advanced cases should be a thing of the past. It is clear to me that these recommendations are severely flawed. Recommendation comment: Without question screening is essential. Other comments: Anyone found with a PSA above 2.5 should have annual follow up tests. Anyone with a PSA above 3.5 should have an MRI scan.
P506	Affected Comment: I was encouraged by a friend to ask for a PSA test, as he had recently been diagnosed with prostate cancer. Luckily my result was negative, however because of his encouragement, several of his friends (who had never felt the need to think about a test) also asked for tests, and four individuals had positive results and have received various treatments. My friend and his other four friends would not have had a test had it not been for him being encouraged by word of mouth, which makes you wonder what the outcome for those five individuals might have been had this not have happened.

	Surely it is a no brainer for a national screening to be set up for men over 50 to have a regular PSA test, as we all know that risk increases with age. We are constantly being told that 1 in 8 (or 1 in 4 for BME) men will get prostate cancer, and is the cause of most deaths due to cancer, but the attitude of the UK NSC seems to be stuck in the monetary cost, rather than the emotional cost to those families who are likely to be affected by this lack of screening.
P507	Affected Comment: This is a condition that i am currently undergoing treatment for, and that led to my fathers early death. Evidence Comment: I have not had sight of the evidence, or the technical knowledge to comment. Discussion comment: My concern is that the human factor has not been considered. I agree with the comments that the screening process is stressful and at times plain unpleasant, but that is better than the alternative of not finding the problem until too late. I had no syptoms and asked for testing because of my fathers history. Men generally wont generally ask for screening but many will go if invited. Most men i have spoken to actually believe that they will be invited to their gp for testing on a routine basis and are surprised that this isnt the case. As a result i believe that the lack of screening is fundamentally flawed. Certainly my own cancer would not have been found yet if i hadnt demanded a test, and i believe many men will be missed under the proposed system. Recommendation comment: As above. There is general ignorance amongst men, who will not go for screening unless invited. Consequently many cases of cancer will not become evident until too late and this will cost lives, and likely add to the cost of treatment etc to the nhs. Some form of screening, coupled with education, is in my view essential. Alternatives comment: I dont believe there is a good alternative to screening. Proper education and regular publicity about the risks, and that the onus is on the individual to get tested is also essential. This must be repeated frequently and gp s should be trained to specifically ask men about their history.

	As a minimum, If there are any risk factors gp s should be recommending repeat testing at regular intervals. In my case, whilst my gp was helpful and quick to react after my psa test i did not have any prior advice despite the practice having been told of my family history. Other comments: Education and regular screening are in my view essential
P508	Affected Comment: I have several friends who have been treated for prostate cancer this prompted me to get tested even though I had no obvious indicators. Turned out I had middle stage cancer and have very recently had a Radical Prostatectomy. If I hadnt listened to my close friends stories I might have left it 5 or more years before being tested by which stage pretty sure it would be advanced stage cancer I would be dealing with. I was not aware until very recently the PSA test was a simple blood test and I had been avoiding the rectal exam. If I had had recieved more information from my GP along with the heap of "please come in for an MOT" texts and emails I would have acted even sooner. I consider myself extremely lucky and fortunate to have accidentally stumbled upon a diagnosis aged 55 and had time, age and fitness to fight this when I have instead of much later in life when the disease had spread beyond the Prostate. Dread to think how many men are not so fortunate or lucky !!!! Evidence Comment: I do not, I base my thinking on my personal experience. I in no way fitted the standard 'At Risk' criteria and yet had middle stage cancer none the less. Discussion comment: It needs to be reversed, a National screening program must be in place. It seems ridiculous that it is not when it is the biggest killer of men in this country.

	Every male I haev spoken to who has been impacted by Prostate Cancer believe this decision to be outrageous, we cant all be wrong Recommendation comment: Screening should be a must. I had zero indication I had middle stage cancer and felt no need to get tested. Fact that I did afetr talking to a close friend probably saved my life. I am *****, my daughter is *****, wife *****, for cancer to pluck me from this before I hit ***** was a very real outcome if action had not been taken when it did. Alternatives comment: Better education, active program of information from GP's to go along with the endless "your cholesterol is high we want to put you on statins" that is a fact of life once you get past 40 !!! Other comments: NHS should seriously review the viewpoint that all cancer is genetically inherited. There is no history in my family of prostate cancer affirming my belief that I was not a risk. Greater focus should be put on life style, diet and exercise, fasting etc. And debunk the notion that genetics are the be all and end all of assessing your risk
P509	Affected Comment: Most certainly! I attend many more hospital appointments, in addition to increased blood tests. My social life is restricted due to a lack of energy, Recommendation comment: As PSA is no real indicator, cancer screening of all males over 50 is the only way we can be sure if the condition is present. Alternatives comment: Realistically, increased funding would help, but this seems to be a non-starter.
P510	Affected Comment: Yes, it affected a very close friend of mine, who thankfully was treated and is a survivor. This aside, screening should be made available to everyone – giving them the choice, as with breast screening, to have a check every two years. Would there be any reason why it couldn't be done in the same way? We see the mobile vans all over *****, where I live. It's a constant reminder that it is available. Evidence Comment: I am a member of the public I have no clinical knowledge.

	Discussion comment: No, I dont feel I am qualified to comment. Recommendation comment: All I know is this should be an available screening service. Alternatives comment: Use the same processes as Breast Screening, this works. Other comments: As with any cancers there is a greater survival rate if found early – we are always told.
P511	Affected Comment: ***** years ago at the age of ***** I was diagnosed with terminal prostate cancer I didn't go to the doctor because of this I went about something else and during the consultation with the doctor I was advised to take a PSA test this came back with a reading of ***** if I had been offered the test at 40 or 50 this would have been found at a time when it could have been cured because it would not have spread to my lymph nodes and lung because of this government denying men this test I am going to die this is very hard for me and my family as the doctors have no idea of the time frame all they can tell me is at some point I am going to die Recommendation comment: Yes it should because as I have said above I would be able to watch my grandchildren grow up and look forward to my retirement after a long period of working and paying in vast amounts of money into my pensions I will be getting very little back Alternatives comment: I think a simple blood test is adequate takes seconds saves lives
P512	Affected Comment: I have prostrate cancer and my life has been turned upside down side down Sleeping urinating life style limited need to pass water very often leakage if was screened earlier I feel action could have reduced the impact on my life Recommendation comment: Yes early diagnosis prevents early death

P513	Affected Comment: It's has totally affected me and my family. It is a massive worry that I may have now passed this onto my son. For me when I got diagnosed it's totally changed my way of life. I have totally changed in what I drink, I only drink water and when I do drink tea it's decaf. My mental health has been affected terribly. I can't thank ***** and ***** enough for what they have done, they are just absolutely fantastic. My anxiety is terrible which I've now been given another tablet but it's certainly working just now. After receiving ***** sessions of radiotherapy and hormone tablets for ***** years, I'm still getting my hormone injections it has now spread. It is in my ***** which I've now to let it grow some before I get more treatment. There saying that my next treatment will be chemo. Which I'm getting told to try and carry on as normal, just tell me how that's possible. Evidence Comment: Just why isn't there a national screening for men as prostate cancer is now the biggest cancer in Britain. Discussion comment: Just to get every man at 50 years old to get his psa checked Recommendation comment: Yes definitely every man at 50 should get a blood psa test done. For me my psa was only ***** and my ***** in the gleason scale. Which my psa isn't high but I'm nearly at the top of the gleason scale. Which is worrying. Everyone keeps saying the earliest you catch it the better and if you have to get a cancer it's the best one to get. I personally wish I hadn't got it. I just don't understand why men can't get the blood test. Alternatives comment: What other alternatives are there?????? Why is it charity's that give all the support not the government I was personally all over the place until I got the support firstly from ***** which I can't thank enough ***** was absolutely amazing. Then the support from ***** and again fantastic and amazing support. Other comments: Give men at 50 and then every year after a pas blood test. And improve the support network please 🙏

P514	Affected Comment: Having ***** diagnosed for prostate cancer in ***** and thereafter received ***** radiotherapy treatments. I now find no trace. This condition was found as my wife said I was urinating too often and told me to see about it. I was lucky but many others are not. That is why we urgently need a screening programme for every man and cut the incidence of death as a result as it can be cured if caught early. Evidence Comment: I'm sure you did not receive all the relevant advice or you would not have come to the conclusion you did Discussion comment: Just do the right thing now. Recommendation comment: Screening is urgently needed to save lives. Alternatives comment: Have GPS test blood as a matter of routine. Especially when taking blood for other reasons. Other comments: None than already stated here
P515	Affected Comment: I had no symptoms. If I had not asked for a PSA test I would still be unaware I had localised advanced prostate cancer. I am ***** and if regular screening was in place I would have probably not required the amount of treatment I am now looking at to try and control the cancer. Earlier diagnosis could save the NHS large amounts of money and many lives. Recommendation comment: Yes it should it is a lifesaver Alternatives comment: Being made more aware of the condition and that sometimes there are none or very minor indications that you have the cancer Other comments:

	Screening will save many lives and the cost of the test and initial diagnosis is not a lot or even a complicated or uncomfortable process
P516	Affected Comment: Yes, my husband was diagnosed following a *****. He had no symptoms and was *****. Prostate cancer/ screening was never mentioned to him at any GP appointments and do only had a PSA test because of this *****. Thankfully the cancer was contained within the prostate but was against the wall, which meant was close to breaking through and spreading. If he had not had the screening it would have led to a terminal diagnosis which is a terrifying thought. Our son is now at a higher risk and he has been advised to have his PSA checked from ***** , which I fear he may struggle to get. Evidence Comment: My husband's cancer was only picked up through screening. Our GP surgery is not proactive and never mentioned screening for my husband so GPs cannot be relied on to target men. My son has been told by my husbands consultant to get tested from ***** and he will not even be screened, yet he is at a higher risk than most. As mentioned previously my GP surgery are not proactive on this issue and I worry he will have to fight to get tested. The review has disregarded men in this category and have classed them as at no higher risk than the general population which has been proven not to be the case. Discussion comment: It is wrong to exclude men who have a close family member and also black men from the group who should be screened. The only group who are recommended are those with a genetic link which most men would not be aware of. This would mean genetic screening which has a higher cost. It is proven that men with a close family member who have been diagnosed and black men are at a considerably higher risk than the general population but they have been excluded from the recommended screening program. Why has clinical evidence been ignored? Recommendation comment: Please see my above responses Alternatives comment: Could is a very loose term. There is no other way to initially test for a possible prostate cancer diagnosis. The only other way at the moment is biopsy but that is even more impractical.

	Unless another,more reliable way is found PSA screening is all we have and should not be disregarded. PSA screening is not 100% reliable but without it my husband would have terminal cancer and may have died already. Instead he has had radiotherapy and is checked every 6 month by a PSA test. Ironically it is a good enough test to tell if he has been treated successfully but according to the reviews conclusion,not a good enough test to screen men,especially those in higher risk groups. Other comments: Yes stop putting cost before mens health. Women have breast and cervical screening, which can also give false results but these tests still happen. Why are men not afforded the same care?
P517	Affected Comment: I was diagnosed with prostate cancer in *****. I had no symptoms and it was found "by chance". I had a recurrence at the end of ***** and further treatment in early *****. I am now on hormone therapy which has several side effects. Evidence Comment: No comment Discussion comment: No comment Recommendation comment: Yes, screening should be recommended. I am a white Briton, so not in a high risk group. There is no history of prostate cancer in my family. I had no urinary problems or any other symptoms. My cancer was only found by chance when I visited the GP for something else. Alternatives comment: Quicker access to PSMA scans on the NHS. I was told in ***** the waiting list was ***** months. I am fortunate enough to be able to pay and go private for the screening (more than *****). I firmly believe that a ***** month delay would have been very serious for my health as the cancer had already spread outside the prostate to the lymph nodes. Other comments:

	No comment
P518	Affected Comment: My father died approximately 6 months after being diagnosed with prostrate cancer. As a family it was horrible watching him suffer during that time. As I am now at a higher risk of also having prostrate cancer I have been trying to have a PSA test each year. This has not always been easy and seems to be dependent on the gender of the individual you see.
P519	Affected Comment: Yes my husband recently lost his battle with prostate cancer. He was diagnosed ***** years ago, he had few symptoms and was healthy living a full life. Going to the toilet had become frequent so he went for the test, to our shock he was ***** and the cancer was in his bones already. My father died of prostate cancer too very similar. Screening would have saved them both. This is 2 people I loved the world and it is unnecessary suffering and early death. Also the pathways desperately need reviewing and updating in line with new age drugs. Medicine has moved on but pathways haven't. My husband was tested with Aberiterone but never scanned in ***** years whilst psa remained low his cancer spread in neuroendocrine small cell leading to very traumatic end of life experience. New age drugs need new pathways Evidence Comment: I think the cases of late diagnosis and their debating effects are not being understood or acknowledged. On otherwise healthy people this disease is running rampant without symptoms until it's too late. My husband and dad would not have been considered high risk. Just get people tested like cervical, breast cancer programmes. I have seen some charities set up a Man Van where people can get tested on mass. Go to where men are ...sporting venues and get

	some quick action. I don't understand how it takes so long to make these decisions. Life's are at stake here, how many more of our men have to needlessly suffer and loose their lives. Discussion comment: I just don't see that it's going to make a massive difference it's cautious and only covering certain criteria – everyone needs access to screening Recommendation comment: Yes should be recommended along with updated pathways Alternatives comment: My husband couldn't even receive any financial support he's worked since ***** full time and then in need couldn't get any support. Not until he was on end of life – disgusting, he received ***** weeks money then when he passed they asked for some back – the last thing a widower wants to be dealing with. Also some of the harrowing symptoms were not fully acknowledged or understood /supported. I wish someone would fully understand exactly what it's like to have this advanced disease and speak to people like myself and the those with the disease. Feels like no one is listening Other comments: Listen, speak to those directly affected not just a questionnaire listen to this experiences
P520	Affected Comment: I have been diagnosed with metastatic prostate cancer and am about to start chemotherapy. I am symptom free - so if I had not asked for a regular PSA test - I would be unaware of the cancer that is already in my bones and lymphatic system. Evidence Comment: The most common symptom of having serious prostate cancer is - no symptoms at all - until it has developed significantly and potentially dangerously so. Discussion comment: The PSA test – while not perfect – is relatively cheap and easy to administer. Recommendation comment: The PSA test is currently the best way of easily picking up prostate cancer before more serious symptoms are evident and so is a potential life saver. Alternatives comment:

	"People with the condition" can't be helped unless the NHS are aware of who they are. Awareness campaigns are useless when many will be symptom free – as I am. Other comments: Prostate cancer is now the most common cancer in the UK. There is a lot of research into it, but further research into a better testing, targeted scans and treatment must be a high priority.
P521	Affected Comment: My brother, my uncles(two) have been diagnosed with prostate cancer.i'm not sure I 'm qualified to answer this.Once again, I'm not sure I'm qualified to answer this. Evidence Comment: Once again not sure if I'm qualified to answer this.Not sure I'm qualified to answer this either. Recommendation comment: Screening must be done for all men. Too many men have already succumbed to this terrible condition without screening. Screening would identify those most in need of treatment and give the appropriate advice in all cases. Alternatives comment: More information on the condition and the symptoms, if any, to look out for. I am aware that not every case has visible symptoms and many don't know they have the condition until it is too late like my two uncles.

P522	Affected Comment: My husband was diagnosed with prostate cancer at the age of *****. He had no symptoms whatsoever and asked for a PSA test purely because of all the publicity surrounding Sir Chris Hoy and his situation. Although he has a strong family history of cancer, he was never offered any kind of early screening and it is only because he is registered with a good medical practice that his GP agreed to testing. He has now been on hormone treatment for ***** and also been through ***** of radiotherapy. He has ***** of hormone treatment to go and these things aren't without their side effects. He's tired, energy levels are low. He needed to be close to a loo at all times for a few months but thankfully that has improved now, so many men suffer far worse. As his wife, it's a scary journey for both of us and I think sometimes it's in my head even more than his. He had zero symptoms... I shudder to think where he might be if he had waited for symptoms to appear, or if his GP had refused him that first PSA test (as so many are). We have national programs for breast, cervical and bowel screening. Why are we denying so many men (and their families) a chance at a longer life together just because of a small blood test? I work in the NHS. People get blood tests every day for things that may or may not show up. The vast, vast majority of blood tests come back negative. Great, that's reassuring! These tests are often carried out to "narrow the field" in pinpointing a diagnosis. Why then are we denying men a simple blood test, which if positive, can lead to earlier and easier treatment IF it does end up being prostate cancer? Surely prevention is better than cure and the costs of running a screening program would be far less than the costs for more invasive treatment when cancer is discovered far later. That's before we even look at the human cost... families decimated by something that could possibly have been avoided altogether by a simple first step screening program. Do we value our men's lives that low? Please reverse the decision and do the right thing for all men, give them a fighting chance.
P523	Affected Comment: It has not affected me personally but has been the death of several relatives and friends over the last years Evidence Comment: I am not qualified to comment on the evidence for the Review Discussion comment: Yes. I believe in national screening as a weapon in the NHS armoury. I am screened regularly for bowel cancer and the negative returns are always encouraging. Several friends and relatives, however, have had positive results but all caught early enough to stop the disease.

	The Review worries about over diagnosis. I understand that such errors would cause much more work and cost for the NHS; but it would all be value for money since the screening would also catch many more cases before they became lethal; and its very existence would offer encouragement to us all. Recommendation comment: Yes, see above, please. Alternatives comment: We're not talking about "helpingwith the condition", are we? Surely this consultation is about screening for the disease early enough to stop it. Other comments: No, thanks.
P524	Evidence Comment: Absolute disgrace as usual. Government giving no concern whatsoever to a minor opportunity to save lives from a cancer easy to cure if caught early – sacrifices on the altar of money and profit. Unacceptably immoral and you should all be thoroughly ashamed of yourselves. Let's hope none of YOUR relative are unfortunate to get prostate cancer and their lives put a major risk because they couldn't get an early scan – because you deciddd money mattered more than lives. Discussion comment: Absolute disgrace as usual. Government giving no concern whatsoever to a minor opportunity to save lives from a cancer easy to cure if caught early – sacrifices on the altar of money and profit. Unacceptably immoral and you should all be thoroughly ashamed of yourselves. Let's hope none of YOUR relative are unfortunate to get prostate cancer and their lives put a major risk because they couldn't get an early scan – because you deciddd money mattered more than lives. Recommendation comment: Absolute disgrace as usual. Government giving no concern whatsoever to a minor opportunity to save lives from a cancer easy to cure if caught early – sacrifices on the altar of money and profit. Unacceptably immoral and you should all be thoroughly ashamed of yourselves. Let's hope none of YOUR relative are unfortunate to get prostate cancer and their lives put a major risk because they couldn't get an early scan – because you deciddd money mattered more than lives. Alternatives comment: Absolute disgrace as usual. Government giving no concern whatsoever to a minor opportunity to save lives from a cancer easy to cure if caught early – sacrifices on the altar of money and profit. Unacceptably immoral and you should all be thoroughly ashamed of yourselves. Let's hope none of YOUR relative are unfortunate to get prostate cancer and their lives put a major risk because they couldn't get an early scan – because you deciddd money mattered more than lives.

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P525	Affected Comment: I was diagnosed with aggressive Prostate Cancer in *****. I underwent radical radiotherapy combined with hormone treatment. Unfortunately my PSA started to climb again ***** years later and I have been under hormone treatment ever since. It is currently in an upswing again. I have routine injections and periodic bone and CT scans. I was very fortunate that it was just caught in time, before metastasis. A few months later might have been very different. The hormone treatment has of course affected my libido and curtailed my athletic abilities, but we live with it and make the most of life. I have lost ***** close friends to the disease, and who would most likely still be with us had they received a timely diagnosis. My ***** is also undergoing chemotherapy to manage the metastases, which would have been avoided through earlier diagnosis. Had a diagnosis come earlier for me, then I might well have avoided the ongoing issues and equally the significant costs that my treatment continues to impose on the NHS. Evidence Comment: Late diagnosis is a crucial issue, both in terms of the effects on patients, such as myself, those for whom it is too late, like my friends, but also in terms of the load that our treatment puts onto the health service in terms of resources and cost. I believe my medication costs are in excess of ***** p.a. and the scanning costs must be considerably more. I don't feel this bigger picture has been taken into account. Discussion comment: As I understand it, the recommendation is to scan those with a genetic disposition to the disease. Sounds good in principle, but how is this going to be established?

	Recommendation comment: I do think that screening should be recommended. The taboos relating to Prostate Cancer seem to be falling away, and widespread publicity and discussion should help manage the fears and issues associated with scanning and possible treatment. There is the question of overdiagnosis, and invasive biopsies, but modern imaging ought to allay much of this. And a false biopsy is much better than the alternative of a missed diagnosis. And significantly cheaper in the long run. Alternatives comment: What would the alternatives be? Public education is very important indeed, but it still leaves the responsibility to the individual to request screening. Breast cancer and cervical cancer scanning has become a norm for women over the past decades, and barely raises a query. Prostate cancer scanning ought to be the same for men. Other comments: Whatever policy decision is made, it needs to be reviewed regularly to take account of changes and developments in scanning and treatment. It is a fast moving world in terms of technology and medicine.
P526	Affected Comment: I had a radical prostectomy in ***** and know of men who have passed away because of this disease. All men should be screened as a matter of course and this should be implemented as soon as possible, ***** blokes that I knew did not really have "symptoms" to begin with, and by the time they did and were diagnosed it was too late for both of them and palliative care was all they had available. Needless to say this has had a devastating impact on both families with one never seeing his Grandson born. I am now retired and feel strongly that testing should be the "default option", give men the opportunity to be screened at a normal doctors appointment the same as blood pressure checks and listening to your heart. The PSA test potentially saved my life and while it caused a massive roller coaster in my life without it I may not be here writing this. Whoever reads this I want YOU to put yourself in MY position, did I do the right thing getting myself tested? Absolutely!! I have ***** Grandsons now and may never have seen them otherwise, so please look very carefully at this campaign as you will be condemning some "non high risk" men to early death. Evidence Comment:

	All men should be tested! There is no need for any other “evidence” look at the numbers there is no logical reason not to. Some “non high risk” men will suffer from prostate cancer and are having to ask to be tested, whereas it should be done routinely just like the Doctor listening to your heart and lungs or taking your blood pressure. Discussion comment: Get men who have Prostate cancer, have had Prostate cancer on the panels you will be surprised at how strongly they feel as do I. Recommendation comment: ALL men should be screened regardless of ethnicity, Prostate cancer affects men of all races and “high” and “low” risk men alike. I would not have been considered “high risk” but my Prostate cancer was diagnosed early, I had a radical Prostatectomy and am fully recovered without it having spread so consider myself very very lucky. Alternatives comment: All methods should work in conjunction with each other, for example there are “many alternatives” to a screening programme for Breast cancer but there is a screening programme isn't there?? Other comments: Yes, get the Prostate cancer screening programme up and running now not 1 year 10 years down the line NOW!!!

Affected Comment:

I heard about the death of Bill Turnbull in September 2022 and realised I had symptoms that could be prostate cancer. After GP appointment and tests I was diagnosed with locally advanced prostate cancer ***** in *****. Hormone treatment at once, paid for private spacer treatment (£*****) on advice from members of local support group, ***** sessions of radiotherapy from ***** to*****. ***** PSA undetectable. Last Prostate injection *****. Latest PSA (*****). *****.

Through local support group of ***** or so people met ***** men I already knew.

DOB *****. Hormone treatment has made erectile dysfunction worse.

A former ***** is of Afro-Caribbean descent and has had prostate cancer, and helped to publicise it. (I was***** and *****).

Evidence Comment:

I can't comment in detail but it is clear that awareness of prostate cancer needs to be increased.

Discussion comment:

It seems possible that the conclusions are over-cautious, using uncertainty as an excuse for inaction, when a proper precautionary approach would suggest more screening.

Recommendation comment:

Screening should be recommended, accompanied by information like the excellent leaflets from Prostate Cancer UK to reassure men that an early diagnosis can lead to simple treatment with very little if any pain or disruption to normal life, while explaining that delay increases the risk of needing surgery or dying, Screening should focus on men over 50, or less where there is any risk factor such as family history or ethnic background.

Where the result is no or early cancer, medical professionals should be ready to advise that immediate treatment would be more damaging than the cancer, but that the case will be monitored at suitable intervals.

Alternatives comment:

Better public information designed to be factual and to promote awareness of symptoms and risks. It should encourage investigation where there are symptoms but point out that these may have other causes that are also treatable. But it should avoid alarming those who are not affected.

Publicity should be explicit and frank about symptoms.

GPs should be helped to be fully aware of which cases need to be referred for specialist attention.

Other comments:

The options for diagnosis and treatment have advanced rapidly even in the ***** years since my first suspicions. Policy should be reviewed continuously and particularly whenever new evidence is available. It should be led by evidence.

	I am glad that you are asking about the personal impact. Even in a case like mine with a good outcome, prostate cancer is now part of my health story that I am often conscious of, together with all the other ailments that are common among men like me in their *****. But cancer doesn't prevent normal life; I am currently the *****, and working hard for it most days.
P528	Affected Comment: I had PC and had robotic removal in *****. Discussion comment: We need screening Recommendation comment: Yes because it has no symptoms sometimes then it's too late ie Chris hoy Alternatives comment: Get more funding

P529	Affected Comment: Prostrate Cancer has affected both my family and friends Evidence Comment: Prostrate screening should be made available to ALL men It saves lives Discussion comment: Please impliment Prostrate screening on the same lines as breast screening and cervical screening Recommendation comment: As above comments Alternatives comment: Implementation of Prostrate screening Other comments: As above
P530	Affected Comment: I had biopsies and was found to have low grade prostate cancer but was told I did not need any treatment. It would be monitored. I was referred to Urology in the ***** because I had an enlarged prostate and going to the toilet every 2 or 3 hours per night. I was prescribed some tablets which had some awful side effects so they were stopped. I was then prescribed Vibegron but I was already taking Furosemide tablets. One tablet was making me go to the toilet and the other was stopping me going to the toilet. After ***** I was seen about my prostate cancer and the blood test came back no change. I still take the conflicting water tablets and I have been referred to the *****. I have never been spoken to or given any advice from my GP when I was informed by letter that I had prostate cancer. I had loads of questions but never got the chance to ask them or discuss anything about cancer. My father had prostate cancer which was the cause of his death so I was worried about being told I had it. Evidence Comment: Low grade prostate cancer seems to me to be just words on a letter sent out to the patient and the doctors surgery who just seem to file it away and don't follow the supervision part up. The did not discuss prostate cancer with me at all as I was informed only by letter. Discussion comment: I received no treatment for an enlarged prostate that made me go to the toilet until I specifically asked for it. I did not receive any advice or discussion other than a letter telling me I had low grade prostate cancer. No doctors discussion or reason as to why I did not need any treatment

	for cancer. The word itself sends shudders down my spine especially having seen my father in hospital with a canister of morphine under his bed relieving the pain before he passed. Recommendation comment: All men over a certain age should ask for a prostate blood test. It may not be accurate as it should be but it does save lives and the cost of a blood test is minimal. Women have all sorts of tests for various medical problems they are offered and yet men have to ask for a blood test to see if they have prostate cancer. Men should be offered the test after a certain age by law. Alternatives comment: I found the finger being inserted in my backside on more than one occasion particularly unpleasant which I am sure puts men off. My symptoms were of an enlarged prostate and the prostate cancer came to light because of this problem. Other comments: Prostate cancer can effect everyone and anyone and unless it is discovered early it cannot be cured. The only way to discover it early is to have a screening programme and I cannot understand why male politicians do not insist there is a test available to men. There are some very famous and very fit men with prostate cancer so it knows no bounds. The only way to beat it, is to test for it, catch it early and hopefully cure it. There is nothing negative testing for prostate cancer and I don't understand why we are having to plead for a simple test for men to see if they have prostate cancer.
P531	Affected Comment: ***** years ago I went to my doctor for a general check up. As part of the consultation we discussed sleep getting up in the night etc. He felt my prostate which was enlarged but otherwise felt ok. He organised a PSA test, which was within acceptable levels, and recommended an annual follow up PSA test. Three years later my PSA level was just above the acceptable range and I had an MRI scan and a biopsy which confirmed I had early Prostate cancer which was contained and not thought to be aggressive. I now have PSA tests every quarter and recently had a repeat annual MRI scan. This confirmed that my cancer has not grown and for now we continue with surveillance. I am lucky. Even though I have cancer it seems to be a non aggressive type and because I am under surveillance I can probably avoid dying of it if it starts to grow. I had two friends who were not so lucky and only got their cancer picked up at stage 4. Both went on to die of it. One was in his ***** so this was very unlucky. The other one was in his ***** and had he been part of a screening programme he would have had a much better chance of

	survival as it would likely have been discovered much earlier. He spent ***** years receiving the best treatment the NHS could provide including trial participation at *****. I am not a healthcare accountant but I cant believe the cost of screening will cost more than the costs of treatment and end of life care in most cases. The costs outside of treatment can be huge. Single mothers left to care for children requiring years of support etc. Prevention is always better than treatment so please consider this very carefully. Thanks Recommendation comment: I think screening should definitely be recommended. It may have saved my own life. (see section 1) Alternatives comment: A programme of education. Many men over 50 talk about having to get up in the night to urinate. This is seen as just part of being older, and it is part of being older but it can also be a symptom of Prostate enlargement and or cancer. Get sports stars and people who are relatable out on social media talking about the importance of testing. And make sure testing is available without a doctors referral to all men.
P532	Affected Comment: My husband was diagnosed with prostate cancer in *****. He had had no symptoms apart from complaining about backache. The diagnosis came as a result of him not recovering as well as expected from a triple bypass op. Unfortunately by this time the cancer had spread to his bones. He was given a course of chemotherapy initially, then put on Arbiterone. When his PSA levels started to rise again he was given another course of chemotherapy which was stopped when it obviously wasn't working. Initially the prognosis was ***** years – he managed ***** years before sadly dying on *****. Recommendation comment: As I have two sons in their *****. I am obviously concerned for their future and feel very strongly that some sort of screening is vital. The difficulty is that as my husband was not aware of any symptoms how would people be targeted?

P533	Affected Comment: Since leaving the Army in ***** after a ***** year career I have remained in touch with several hundred comrades vis social media. The death rate over that period has been extensive, *****% due to cancer and over *****% of them to prostate cancer. I survived bladder cancer but worry that my susceptibility to the disease, and prostate cancer in particular, is high. Evidence Comment: While clinicians believe diagnosis can lead to unnecessary treatment – the patient is often likely to die of something else before the prostate problem does the job – I believe it is for the individual to weigh the facts and make his decision. A screening programme doesn't require an individual to be screened but allows free choice. I have taken up all the bowel screening opportunities offered to me and had ***** endoscopies as a result with polyp removal occurring on each occasion. Discussion comment: The conclusions feel dated because advances in detection and treatment are being made daily. Late stage presentations/detections make treatment less effective. Again I believe the technology should be made available to those who wish to avail themselves. Recommendation comment: Yes I believe screening should be recommended. Had I not had my bladder cancer detected as the result of a routine urine check during a military health check I would likely have died ***** years ago missing my grandchildren and being unable to provide many years of voluntary service to my community. Screening of the most vulnerable should definitely be introduced as a matter of some urgency. Alternatives comment: Centrally organised prostate cancer testing instead of the current ad hoc system should be prioritised particularly for those who are assessed as being at higher risk. We need clearer access to PSA testing, better GP support and education, improved public information, and action to tackle inequalities in access and outcomes. Other comments: If the decision is not to have regular screening then that policy should be kept under constant review to ensure advances in the field of detection and treatment can be introduced quickly. Scheduling reviews over extended periods is counter intuitive. Screening decisions are complex but ultimately the decision should be the individuals and that decision can only be made if the disease is detected, I therefore strongly believe a screening programme should be put in place now.

P534	Affected Comment: Yes. I have several friends who are on drugs to manage their prostate condition Evidence Comment: Not sure the evidence explored the confusion faced by older men, feeling urged to by media to get checked, with resistance from the NHS to get checked. I've resorted to getting blood checks from Amazon! Discussion comment: No Recommendation comment: Screening should be recommended. This would address the confusion faced by older men wondering what they should do! Alternatives comment: Nothing. Screening is essential Other comments: Please push this topic up the priorities
P535	Affected Comment: My husband has just been diagnosed following his request for psa. He had minimal symptoms and without my Nursing experience he would have dismissed it as aging. He is ***** and otherwise healthy. His PSA is ***** which is exceptionally high and suggests too advanced to expect a cure and prognosis is poor. We are devastated. Had he been routinely screened this could well have been avoided. Saving our stress, saving his life, as well as saving the valuable NHS resources he now needs. Please please please set up screening! I have been a registration nurse for ***** years and this has been an ongoing conversation for the majority of my career. Stop this health inequality now! Discussion comment: This feels like a health inequality in an already hard to reach demographic. Men are noticeably less likely to seek advice. Recommendation comment: Absolutely yes. If more men were aware of what to look for alongside being offered screening it would undoubtedly save lives reduce pressure on NHS resources Alternatives comment:

	Public Information adverts on TV showing symptoms, this is to be aware of and what to ask their GP to do. Being made aware they can request a PSA from their GP
P536	Affected Comment: I have been successfully treated for prostate cancer, so was my father, so was a close friend. My father was a *****, I was a *****, my friend knew a retired ***** (me). Evidence Comment: I feel that the above reply should be taken into account in that men who have information can act on this and be successfully treated. Discussion comment: I feel that, in view of the last answer, men who do not have access to this 'inside information' will present very late for treatment and therefore be at risk. I don't feel the NSC findings properly took this into account. Recommendation comment: Yes, because seeing a health care professional can be extremely difficult. Leaflets and campaigns are not enough. Alternatives comment: I think screening is the only workable option. Other comments: Ask the public what they want.

P537

Affected Comment:

I had a diagnosis of Prostate Cancer in *****. It was found rather late but purely by chance. A consultant for my arthritis did a blood test and for some reason include a PSA. It was this lucky incident that discovered the cancer.

I also have ***** friends who have been diagnosed one again rather fortunately.

My cancer was treated by Radiotherapy and has happily gone into remission for the last ***** years.

Evidence Comment:

It would appear that this form of cancer has now overtaken breast cancer as the most common form of cancer in the country, and this fact seems to have been totally overlooked.

This decision, to me, seems to have completely overlooked this evidence.

Discussion comment:

I believe the decision was more about money than men's health. A dreadful state of affairs.

Breast cancer is now the second most common form but still retains, and rightly so, a screening program, but this consultation sees men's prostate cancer as not deserving of a program. Absolutely appalling.

Recommendation comment:

Absolutely should for the reasons stated above. My cancer was found completely by chance. Had it not been then I would not be writing this today.

The ad hoc system in place at the moment is condemning some men to death.

Alternatives comment:

A screening program is the only way to try to get this disease under control

Other comments:

JUST DO IT!!

P538	Affected Comment: I was diagnosed with prostate cancer after referral to hospital by my GP. Early prostate cancer was diagnosed and I was admitted to hospital for removal of the prostate. It was a successful operation re the cancer, but resulted in no erection. Evidence Comment: No Discussion comment: No Recommendation comment: Yes. The earlier the better. In my own experience, the cancer was discovered and dealt with early enough to save my life. When I went to see my doctor, with which I thought was a minor waterworks problem, cancer was not even in the back of my mind. Alternatives comment: A screening program is an excellent idea. Prostate cancer must be diagnosed early; before there is any chance of it spreading to other organs. There is also a huge financial gain in terms of family income and happiness; Medical and hospital costs, if the cancer can be discovered in its very early stages. In the long term, the concept of a prostate cancer screening test, is to the benefit of the individual and the National Health Service. There should be no question about this; as far as my own experience is concerned. Other comments: I wish you success in getting a Prostate Scanning Test accepted by the National Health Service. It WILL save lives and money in the long term.
P539	Affected Comment: My brother is a person that has the condition, and gone through chemo, and been on a trial to try and control the condition. Recommendation comment: The screening program should be offered for every one reaching a certain age
P540	Affected Comment:

	Toilet visits every 3 hours for pee. Bowl movement very very loose but regular mid morning. Eat Mediterranean diet good olive oil with everything Recommendation comment: I am 82 BUT feel screening is still required.
P541	Affected Comment: My then GP, since retired, literally saved my life, when he requested a routine blood test and included on the the tick box for conditions to be tested for, a PSA Test. I had no symptoms at all, was in good general health and aged *****. There was no history of Prostate Cancer in my family. After a positive result and biopsy, I opted and under went Radical Prostate Removal Surgery, which found my Prostate was the size of a mans' fist and the Cancer I had was a very aggressive form, but, still found to be fully contained within the Prostate. I was very lucky, the Cancer was removed in time and I am in full Remission – ***** other men, whom I got to meet whilst under-going biopsy, consultations and treatment, diagnosed roughly at the same time as I, are all dead, the last surviving another ***** years, with an abysmal quality of life for him and his dear family – it was too late for all of them, other than to delay the inevitable. Evidence Comment: Not aware of the criteria used – thus cannit comment on this aspect. Discussion comment: In the light of known historical and current data and above 90% factual successful complete recovery concerning early diagnosis and treatment of Prostate Cancer, it is incomprehensible that in excess of 12,000 deaths and rising per year, is, apparently, deemed acceptable. Early diagnosis with the advances made in treatment is proven to be highly successful in achieving complete recovery outcomes and survivability. To preside, apparently, over a situation of annual increasing instance of long term intensive and thus expensive treatment costs, not to mention the Human and economic costs and the inevitable ever rising death tolls, for me, is not understood and indefensibly short-sighted. Recommendation comment: The PSA Test, in its current form, is accepted as not being diagnostic of Prostate Cancer. That fact does not indicate to me or, indeed, to many Empirical Studies that it is proper or morally acceptable to, completely disregard, apparently, the PSA Test as indicative that a health issue, probably cancerous, leading to fatality if not treated in time, is occurring in males aged 45 years and over. Prostate Cancer, we know, does not exhibit obvious symptoms in its early stages.

An indication by increased PSA Levels is not to be ignored. It is to be followed up with the purpose of discounting or identifying the early presence of Prostate Cancer. Thus permitting certainty and initiating curative treatment where, increasingly, such treatment is required to preserve life.

There are several promising Research Programmes to identify a definitive diagnostic test for Prostate Cancer in progress, one or two of which are soon to initiate final testing.

Until, such time as the Research Programmes achieve Approval for use in general, the PSA Test is the only method available to begin to reduce the annually rising death toll of men afflicted by a treatable Cancer.

A National Screening Programme for All males over 45 years of age is an imperative and the PSA Test is the only available identifier currently available to do so.

To fail to introduce such a screening programme, in the light of current knowledge, diagnostic and treatment capabilities is to be complicit in the needless suffering and wholly unnecessary death of thousands of males, annually

Alternatives comment:

There may be alternatives to screening.

However, these are not generally known to be significant or successful in reducing the instances of Cancerous conditions.

Whereas the many National Screening Programmes that have been introduced and targeted have undoubtedly proven highly successful in early diagnosis, treatment and successful, often full recovery, patient outcomes.

Other comments:

I don't know, or wish to know the agendas driving the apparent resistance to introducing and implementing a National Screening Programme to, at least, commence bringing down the death toll of current Prostate Cancer Patients.

A PSA screen Test saved my Life, without any doubt.

The many men I have got to know in similar situation to myself, all, are of the same opinion and are in huge admiration and respect for the Clinicians abilities in achieving such high full recovery percentages in terms of early diagnosis.

The tools currently exist and are constantly improving to permit Clinicians to achieve such vastly improved full recovery outcomes, therefore, I submit, assist that provision by a Prostate Cancer National Screening Programme.

P542	Affected Comment: I think that the evidence of prostate cancer in people with a family history or black men in particular shows the increased risk. Personally if they are screened then if it detects anything it can be a discussion with the professionals if it's a watch and wait, biopsy, mri and then people can make an informed decision. Until such time as a definitive test / screening comes out. Too many men are being let down. Please do screening of those most at risk. It must be cost effective to catch things early both in treatment costs and lives ruined (that includes families) Evidence Comment: See as above. Treatment can be a choice for the patient with discussion with doctors. You are playing god otherwise Discussion comment: Think the review is too blunt an instrument and look at Sir Chris Hoys situation. Horrific. Give patients choice and information. Recommendation comment: I think it should be done for all men but if not those most at risk. Alternatives comment: Can't see what alternative there is, Men are notorious for not wanting doctor's intervention but at the moment they have to actively request a PSA test at the doctors. This feels like a blocking tactic. They get asked why do they think they need one! Answer because they want to check they don't have cancer. Simple answer. Don't make it difficult for people! Other comments: Listen to the population and give them choices. It will be cost effective to do so.

P543

Affected Comment:

I was diagnosed with Advanced Prostate Cancer in ***** following an extremely high PSA blood test result. I was aged ***** yrs at the time. I can categorically confirm that I was not displaying any of the 'normal' signs of a prostate problem and it was only after my wife suggested that I ought to have a PSA test that it was RELUCTANTLY added to a routine blood test at the time. In other words, my doctors' surgery were very much against agreeing to the PSA test being included on my routine blood test request.

I cannot complain at the Hospital /NHS treatment that I have received since my diagnosis but I strongly feel that had a routine 'Screening Programme' been in place, my predicament would have been 'spotted' countless months/years sooner! and yes it has profoundly affected me, my wife, my family and my friends

Evidence Comment:

I am not privy as to how the evidence was compiled or presented to the UK NSC but I do feel that not enough attention was given to the 'man-in-the-street' as my above scenario shows.

Discussion comment:

If it was considered that the PSA test was 'unreliable' then why are we still using it? Surely if a screening programme was introduced based on the PSA test, it would be a simple enough change to a more reliable one when it became available?

Recommendation comment:

Wholeheartedly and emphatically YES

Alternatives comment:

It could start with all GP's and medical staff being made aware of the benefits of spotting the cancer at an early stage and recommending the need for testing at the appropriate time rather than the current instruction which actively discourages Doctors from recommending such action!

Indeed, my own Doctor some years ago actually told me that "men these days die WITH prostate cancer rather than "BECAUSE" of it!

Other comments:

Look, the statistics say that 1 in 8 men will contract Prostate Cancer some time in their lives.....IS N'T THAT ENOUGH?

P544	Affected Comment: Following my diagnosis of prostate cancer my sons were encouraged to get tested. One was clear and the other is having his Prostate surgically removed next week. Both like me had no symptoms. Screening could encompass a huge number of patients if a prostate blood sample was included in very blood sample taken for any reason. Many lives would be saved. I was shocked at a recent lunch gathering of old work mates and their wives. Out of ***** men at the table ***** of us had prostate cancer. Recommendation comment: Screening should definitely be carried out, as I said earlier whenever a blood sample is taken. That would catch a lot of sufferers without them having to consciously taking any action. Thats not to say that other screening should be ignored. Alternatives comment: PUT MORE MONEY INTO RESEACH OF THE CONDITION and more support into the charities looking into Prostate Cancer Millions of people are doing selfless acts to raise money for various charities which should be fully funded by Government. I feel most people would be willing to pay a little extra for that to happen Other comments: Lets have a proper democracy. Small proportions of the total public rule over the majority at present.
P545	Affected Comment: I was diagnosed after requesting a psa be added to a general blood test via my GP. I was having more regular trips to the toilet in the night and didn't know if it was just age (*****) or something else. The result was just over the acceptable range and my GP referred me for further tests, digital, MRI, biopsy followed. Result low grade prostate cancer being monitored as advised. This has been a relief knowing it is very probably not an aggressive cancer and may not cause me future problems but is being monitored. The MRI also highlighted another concern, which had no symptoms, and I was referred to another department resulting in the removal of an early stage colo-rectal cancer. Evidence Comment:

	From a personal point of view I did not find going through the tests or results stressing, I would rather know the results. It was never suggested that I should have any other treatment and monitoring was advised. Surely over treatment would not be advised by the NHS Consultant if it was not in the patients best interest. Recommendation comment: I think targeted screening should be carried out and future treatment then left to the judgement of the NHS Consultant. Alternatives comment: More encouragement for screening and acceptance by GP's to offer it. Other comments: Keep things under review as progress is made on diagnosis and treatment.
P546	Affected Comment: My husband was diagnosed with prostate cancer in his *****. His only symptom was to briefly have blood in his urine. His PSA was still quite low. If it wasn't for his concerns and the diligence of our GP it may have gone unnoticed for years. Following further investigation prostate cancer was confirmed, his prostate removed and is now a healthy(ish) ***** year old. We have a son aged ***** and I am fearful that he could be susceptible to prostate cancer. There is a history of breast cancer and other hormone related cancers in my husband's family. I strongly believe screening should be available for all at risk men. Evidence Comment: Nose above Recommendation comment: I think screening should be available for all men in the same way breast cancer screening is available for women. If not all men then at least those who are high risk and have a family history

P547	Affected Comment: I was born in ***** and was diagnosed with Prostate Cancer in ***** following a voluntary PSA test. At the time I had no obvious symptoms. Evidence Comment: Based on my own personal experience I feel so frustrated that the UK is unable to provide men with a formal and organised prostate cancer screening programme. Based on my own experience is just seems and obvious thing to do. Discussion comment: It might be that screening won't capture all cases but if it prevents many then that can only be a good thing to treat this horrible disease. Recommendation comment: Screening absolutely should be recommended. Prevention is better than cure both for the patient and the burden of treatment costs. Alternatives comment: No. There can be campaigns, education which are all worthy and necessary, but the bottom line is that there needs to be a national screening programme for all males over 50 years old. Other comments: Please get started as a matter of urgency. Early diagnosis and treatment will save lives.
P548	Affected Comment: A visit to my GP because of too may night-time loo visits and he accurately identified an enlarged prostate (not too unusual given that I am ***** years old). There then followed almost one year of hospital visits for CT scan, MRI, biopsy, HOLEP operation, ***** radio therapy sessions. Then finally ***** Hormone injections over the next ***** years followed by blood tests and consultations with my oncologist. So to say that prostate cancer pretty much took over my life for that period would be fairly accurate. Evidence Comment: I've now had several PSA readings after each blood test and all have identified my PSA as being ***** . Thus, I consider myself to be very lucky given the treatment I received all on the NHS. Discussion comment: I think it should be recognized that prostate cancer is not something that can be cured overnight. It is a disease that takes over the person's life until, hopefully, it is cured. Recommendation comment:

	I believe that a PSA reading is not taken during a standard blood test and is only taken if specifically requested. This could be changed such that the PSA reading is automatically included as part of the test. This not total scanning but it would be simple to implement. Alternatives comment: See the above comment. Other comments: Keep making people aware that prostate cancer is now the most likely cancer affecting the male population.
P549	Affected Comment: My husband was diagnosed with prostrate cancer in ****. He was aged ****, no family history and no symptoms. A routine blood test for cholesterol and a gp who decided to add psa, probably saved his life. He had since had treatment. Evidence Comment: Having researched, as a partner of a patient, the literature available, what struck me was that more recent research indicated the wider range of treatments available, with significantly improved outcomes, both in life expectancy and side effects. Discussion comment: Every man should have the opportunity to have their psa tested. It should be as routine as cholesterol testing. When caught early prostrate cancer treatment is less invasive, more effective and cheaper! The process needs to be clearly explained – many men are put off by what they think is still a rectal examination rather than a simple blood test. Recommendation comment: I have met men who have been first diagnosed with stage 4 prostrate cancer that has metastasised to their bones and listened to the treatment they have undergone, perhaps you should ask this group if they feel psa screening should be routine for every man. Those I spoke to feel strongly that it should be. So YES I think screening should be offered to everyone with clear explanations of the process and reasons why it is a good idea. Alternatives comment: Wide spread campaigns are good but to consider * not all men have symptoms.

	* Enlarged prostates can give similar symptoms * men need educated that this is not a 'finger up the bum test' as my ***** thought when he visited his gp. He was nervous about going for the test and it was only because his ***** had been diagnosed with prostate cancer that he went. Other comments: Save lives and improve outcomes by routine testing- surely it must be cheaper in the long run * less expensive radiation * less operations * less ongoing treatment * a healthier workforce Increase men's education and awareness Add to schools' PHSE curriculum so young men are aware from an early age. At least routinely target those most at risk ALL black men and those with a family history. And finally, review the policy every two years. Research in this field is fast moving, save lives and improve outcomes, for example the TRANSFORM trial taking place in York by PCR will give valuable insights.
P550	Affected Comment: At least one brother has indications of prostate cancer. Many men live in fear of it and wish there was a simple screening process that could help us. Evidence Comment: While I think the clinical issues were considered, I do not feel that the moral and social issues affecting men were given enough weight. This is a frightening cancer that despite affecting many men does not get treated for routinely. Sadly many of us won't ask for the check available, but a simple screening would cover this. Many older men have an annual blood test so a simple test added onto this would help save many lives. Discussion comment: While I appreciate that it is difficult, I feel that the recommendations are only clinical, based on cost. They have not really accounted for the mental issues suffered by many men regarding this. Recommendation comment: Yes, I think screening should be offered. Many men (not only older ones) already have an annual blood test re medication and cholesterol and other issues etc. This could easily be extended to include checks for prostate cancer through PSA. It could even be something that's

	offered rather than done automatically. A simple add on to these annual checks would be effective and efficient and would not require major changes. Alternatives comment: Anything that helps catch the condition early and then supports the patient is welcome. As mentioned, a simple add on to the existing annual blood checks done by many would be helpful. Other comments: Would it be possible to test the blood given by blood donors? Again, this could be something that's offered rather than mandatory, or perhaps over a certain age. This would be relatively simple to do if the donor agreed.
P551	Affected Comment: Both my father and elder brother were diagnosed with prostate cancer and, with appropriate treatment, survived. Discussion comment: For the YHEC review to have found that the economic model used by the National Screening Committee to reject prostate cancer screening is not fit for purpose is a serious indictment of their findings and the NCS decision must be reviewed once their source material has been validated as correct. Recommendation comment: Screening should definitely be recommended, particularly for men who are identified as at risk.
P552	Affected Comment: I was diagnosed as with Prostate Cancer in *****, so this has directly affected myself, my family and my friends Evidence Comment: I had no symptoms and no history in my family, my prostate cancer was caught by chance and I am not alone with this experience. 1000's of lives would be saved with a national screening program I consider this as vital evidence which was overlooked. Discussion comment: Without a national screening program you are leaving diagnosis to chance and it is not a post code lottery situation it is dependent on how vigilant your own Doctors practice and processes are. Recommendation comment:

	Absolutely it has to be recommended. Otherwise men like me who don't have a history of prostate cancer in their family, do not have any symptoms, will then be reliant on the diligence of their doctor, that is extremely unfair on the individual, their family and the Doctor and as a society, as a human race we owe diligence, doing the right thing, saving lives as a bare minimum to each other. The decision must be made to save lives. Therefore, screening must be recommended. Alternatives comment: There are no alternatives to a screening program Other comments: Get on, stop wasting time and implement the screening program, start saving lives
P553	Affected Comment: I had RALP surgery in.***** At my follow up consultation with surgeon in ***** he advised that my PSA level is now *****. I am cancer free. Surgeon also advised that had my PSA test not flagged up potential of Prostate Cancer then I would be dead in ***** years Evidence Comment: I do not have the necessary technical knowledge to comment. Discussion comment: As previous question. Recommendation comment: I strongly believe that screening should be recommended. From personal experience I was unaware I had aggressive PC and would be dead in ***** years. Alternatives comment: Is it not better to test and risk false positives than identify PC too late to do anything about it. If PSA results in a false positive then the biopsy would be more conclusive. Are we weighing up the NHS cost of an initial consultation with a surgeon and a biopsy against treating someone with terminal cancer ? Its a no brainer for me, introduce mandatory screening Other comments: Introduce mandatory PSA blood test asap.

P554	Affected Comment: I have family members and friends who have been affected by Prostate cancer Evidence Comment: No Discussion comment: Nothing to add Recommendation comment: Screening should be recommended as a must have the same as Cervical & breast screening. A simple blood test every year could not only pick up on Prostate issues but at the same time could be used to screen for other diseases to prevent and save money in the future on treatments of other diseases that could have been avoided. Alternatives comment: Awareness through advertising via TV, Radio, social media and texts. Other comments: Not at the moment
P555	Affected Comment: I have Prostrate Cancer, it went undetected despite having PSA Tests which all came back normal. It was discovered when I had a MRI scan on my liver, and they found a shadow on by spine. The cancer had spread from my prostate Evidence Comment: why are they so reliant on the PSA test, when it does not flag all prostate cancers. The oncologist told me, mine as an aggressive cancer that does not show up on PSA Tests Discussion comment: The conclusions feel overly cautious, whether uncertainty is being used as a reason for inaction, or whether the discussion reflects rising diagnoses, late stage presentations and inequalities. Recommendation comment: Targeted or risk-based screening is a sensible first step, that men at higher risk deserve earlier assessment and clearer pathways, and that while you understand concerns about overdiagnosis or overtreatment, you believe these can be managed in a modern health service. Alternatives comment:

	You could have organised prostate cancer testing instead of the current ad hoc system, earlier risk assessment for higher risk men, clearer access to PSA testing, better GP support and education, improved public information, and action to tackle inequalities in access and outcomes. You need to find a better screening than the PSA Test, one that flags up all Prostrate Cancers Other comments: You need to keep policy under active review as new evidence emerges rather than waiting every 2,3 or 5 years to re-review this, the importance of involving patients and communities in future decisions, and the need for urgency while remaining evidence led. That while screening decisions are complex, you want lived experience to be considered alongside clinical evidence.
P556	Affected Comment: I had a routine ultrasound for another potential issue and the clinician spotted I had an enlarged prostate. The GP then recommended a PSA – I had never at age ***** been offered a test! I have been diagnosed with low grade prostate cancer. My ***** aged ***** had lower back trouble and was found through MRI and biopsy to require immediate surgery to remove his prostate. He had never had a PSA test. Evidence Comment: I accept that the PSA test is unreliable and screening may not always reduce harm but surely the precautionary principle should suggest we need to do more than simply test those with a particular genetic signature. How many men know they have this genetic signature and in more deprived areas the NHS own data suggests many men never come forward for testing or visit their GP. We still need more research on the many outliers, for example my neighbour, who had no such genetic marker but was missed because he never goes to his GP. Much medical research relies on volunteers and consent which could easily build in bias. Discussion comment: The recommendation to focus on the two main genetic markers assumes we already know who to test and this is fraught with difficulties – see my comments above. The key approach ought to be more pro-active with mobile community testing and MRI to seek out and encourage men to come forward for help and advice on prostate (and indeed) all health conditions. This is happening in ***** so why not all of the UK? Informed consent for most men is not a strategy we can trust when good health and treatment seems only to be available for the wealthiest citizens in more affluent neighbourhoods. Recommendation comment: I would support screening of all men over 50. The problems arise when clinicians are over zealous in recommending invasive treatment when risk is low. Surely we want men to be informed fully about their health and able to make informed decisions about their health without fear, pressure. Accepting as normal the fact that thousands of men without genetic markers will

	die from undiagnosed prostate cancer or are left without any contact for years with a GP should not carry on without challenge. There is a need to finally take the health of men seriously and for the NHS to engage with all speed and resolve in a drive to offer much better community health checks with a special focus on men in areas of low income and all black men. Alternatives comment: So many men slip through the NHS net without any kind of preventative work through GPs and local clinics. Lots of men end up seriously ill and thus cost the NHS huge sums of money to carry out life saving surgery or treatment when earlier community screening and education would have avoided this happening. Finding creative ways to engage men who are reluctant to engage with the NHS about the health should be utilised e.g. clinician stands at sports events, in pubs/bars, and through workplaces would be a start.
P557	Affected Comment: Yes I was diagnosed with prostate cancer in ***** and have had treatment with the NH S Evidence Comment: No real consideration seems to have been given to the fact that many men are unaware they have prostate cancer until its to late even if family members have had it. Also the benefits financially to the NHS in catching it at an early stage and savings lives. Recommendation comment: I think it is Very important that screening is recommended as the numbers of men being diagnosed continues increasing. Alternatives comment: It needs to be found sooner rather than later— I know from personal experience
P558	Recommendation comment: Should

P559	Affected Comment: My Brother-in-Law passed away with Prostrate Cancer some ***** years ago. Sadly when he got referred and tested, they found that he had the most aggressive stage, and it had spread to other organs of his body. I have myself have been diagnosed with a slightly enlarged Prostrate, and I take Tamulosin to relax muscles around the Prostrate to allow Urine to pass more easily. I also have friends with this type of Cancer. Evidence Comment: I do think that there should be a National screening process for all men. Women get checked for various cancers, so why not men, as Prostrate Cancer s one of the most serious among men. Discussion comment: I'm listening and reading about what's going on at the moment, and I do think, that more is needed to be done. Recommendation comment: There should be a National screening process for all men, just the same as women are screened Alternatives comment: I really don't have an answer Other comments: Not at the moment

P560	Affected Comment: I am ***** with advanced prostate cancer. I was diagnosed in ***** after I asked for a PSA test. I had no symptoms and no family history of the disease. I would have requested a PSA test in ***** as I had been asking them annually from my GP but due to COVID there was a shortage of blood vials so I decided to wait. My PSA in ***** had gone from ***** to ***** in ***** months and was way higher than it should have been. After MRI scans and biopsies cancer was found in my prostate and spine. I have had a negative brca test so the current proposals would not have picked me up. I am now relying on expensive hormone therapy to keep me alive with all the associated symptoms. I cannot understand the reluctance to offer men this simple PSA test that could have helped me and the ongoing NHS treatment I will require for as long as the hormones keep working. Trying to come to terms with living with cancer, telling my ***** daughters and ***** grandchildren of my condition was the most stressful and mentally challenging experience. I have told male friends to get tested. Evidence Comment: Many friends have had PSA test on my suggestion, two of which had no symptoms – one had prostate cancer successfully operated on as it was caught early. The other was diagnosed with advanced bladder cancer and is currently still undergoing treatment. A simple blood test might not be that expensive or reliable but it is a start and could end up costing the NHS less after the first few years when routine changes can be compared for each patient. Discussion comment: Please allow screening to men as they are being discriminated against when women get breast screening and cervical cancer screening as a matter of course. Recommendation comment: Please allow screening to men as they are being discriminated against when women get breast screening and cervical cancer screening as a matter of course. Alternatives comment: I don't believe there is an alternative to screening as the comparison on year on year could be far more reliable.
P561	Affected Comment: No one affected Discussion comment:

	In favour of all recommendations Alternatives comment: Screening holds primary importance
P562	Affected Comment: I was diagnosed with Prostate Cancer in ***** aged ***** and had a radical prostatectomy operation. Also my father died of Prostate Cancer in ***** aged *****. Also my late mother had breast cancer in ***** which was successfully treated having been identified. My diagnosis only came about as a result of requesting a PSA test otherwise I would not have known. Recommendation comment: Yes. My diagnosis only came about as I had requested a PSA test even though I was not displaying any obvious symptoms. I had the test (aged *****) as my father had died in ***** of prostate cancer aged ***** having been suffering for many months. My cancer was aggressive but fortunately caught before it had a chance to spread. Without the PSA test I would not have known until it had become worse. The cost of screening is a small price to pay if it saves lives. Women have it for breast cancer so why don't men for prostate cancer?
P563	Affected Comment: Yes this is a condition which has affected me. I have had prostate cancer. Evidence Comment: No Discussion comment: I think concluding that screening should not be recommended because of unnecessary treatment is flawed. If treatment is administered it done so after a series of examinations-not just on the basis of a PSA test. I can't help think there is concern that the NHS could not cope with the follow up examinations, therefore the decision to not screen using PSA was recommended. Recommendation comment:

	Screening should be recommended because it is only step one. If clear no further action. If positive then further tests are required before any treatment would take place. In addition with screening men could regularly get themselves checked. Alternatives comment: There needs to be a comprehensive communications plan. There also needs to be a very targeted campaign to communicate with members of the black community. would also recommend working with employers who employ predominately men and carrying out PSA tests in the workplace as some charities do already.
P564	Affected Comment: My husband died in ***** – by the time he was diagnosed he was stage *****. There may have been a chance for his survival if he had been called for routine screening. He did the bowel cancer screening because he was asked and sent the kit. With Prostate cancer being such a big killer and so treatable if caught earlier why is routine screening not standard. It makes no sense. He was a hard working man who paid his dues and was diagnosed a month after he retired – cruel is an understatement. Discussion comment: Time to think again – make routine screening available immediately Recommendation comment: Of course it should be offered – many men don't understand the risk and symptoms and may have white coat syndrome – but with support from partners and family and more openness about this cruel cancer, I feel sure the take up would be high. Alternatives comment: More advertising and more time for Doctors/Nurses to routinely bring up the subject directly or indirectly at other appointments. Prostate cancer symptoms and risks were never discussed with my husband even though he did attend blood testing for checking other medication risks 6 monthly Other comments: Please just do it

P565	Affected Comment: Yes. Despite no family history of Prostate Cancer and NO SYMPTOMS I was found to have a raised PSA during a routine blood test for slightly raised cholesterol. A range of tests, scans and biopsy then discovered that I have advanced and incurable Prostate Cancer, which had metastasised to my hip bone and I was told to expect, on average, ***** years of remaining life. I have ***** sons aged ***** and ***** who I now encourage to have screening. Evidence Comment: How could my Prostate Cancer have been discovered earlier, with no symptoms and no family history and therefore nothing to suggest that I should be tested for the 'markers'? Reliance on these 'markers, is totally inadequate! Discussion comment: This is a short-sighted decision which does not take into account situations such as mine (described above). There are many others like myself, who will be presented with a death sentence because of this decision. Recommendation comment: Yes. Although PSA testing is not totally reliable, it can still identify potential problems. Alternatives comment: I do not know of any other alternatives. Other comments: Please think again, for the sake of my family and others like me who, without screening will discover the problem too late.

P566	Affected Comment: I was diagnosed with early prostate cancer as an incidental finding following investigation of a urinary infection and orchitis. A PSA test showed an elevated level and an MRI scan and biopsy confirmed the diagnosis and extent of the lesion. I was fortunate to get an early diagnosis and SABR radiotherapy so my prognosis is good. Other men without screening might not be so fortunate. Evidence Comment: I am commenting from a patient perspective. I feel that the review of the evidence for screening does not reflect the reality of prostate cancer as a condition affecting so many men and that the harms of late diagnosis and opportunities for treatment are underplayed.. I don't believe the review fully recognises the impact on high risk groups and inequalities in society. Discussion comment: I was very surprised by the conclusions of the review and they are feel overly circumspect such that their caution is being used as a justification for inaction. I do not see that the conclusions represent the imperative of rising diagnoses, late stage presentations and treatment inequalities. Recommendation comment: I believe that targeted screening of all men over 50 is a practicable first step. Men at higher risk due to their family history or ethnicity also deserve earlier assessment and clearer diagnostic pathways. Whilst I appreciate concerns about false positive screening results and over-diagnosis in screening these effects may be mitigated by further diagnostic tests and managed in a modern health service. Alternatives comment: I believe organised prostate cancer testing for at risk populations could provide earlier risk assessment for higher risk men. More clearly signposted access to PSA testing, including home-based testing, better GP support and education would help tackle inequalities in access. Other comments: As an individual who has experienced prostate cancer and treatment believe there is a need for urgent reconsideration of prostate cancer screening recommendations. I am further concerned that there should be active review of policy as new evidence emerges. I believe policy should be patient focussed and must involving patients and communities in future decisions,

P567	Affected Comment: Both my father and his brother both had prostate cancer and had their prostates removed. My father lived another ***** years yet it was this cancer which eventually spread throughout his body and killed him. He implored me to ensure I had annual PSA tests and DREs to monitor my prostate health, which thankfully (at *****, around the age his was discovered to be “the size of a grapefruit”) still seems to be healthy. But I do demand an annual PSA, and do not entirely trust its benign findings, and wish there was a more precise and direct test I could ask for. Evidence Comment: I don’t know enough about it to comment. Discussion comment: I was surprised and disappointed at its conclusion and recommendation. Recommendation comment: Most definitely, based on my own experience and knowing the prevalence of prostate cancer in the population. Precisely because it tends to develop very slowly screening should be used to catch it early and thus optimise the efficacy of treatment and minimise its unwelcome side effects/consequences.
P568	Affected Comment: In ***** I was diagnosed with Prostate Cancer. This came as a shock as I was given an annual PSA test which regularly showed me to be at low risk, I am currently at Stage ***** and due to age and other considerations, I have opted for monitoring of my condition. Recommendation comment: I believe that screening should be recommended, Screening of all men (within set parameters) would enable early diagnosis and therefore a better timed treatment response, rather than intense treatment at later stages of the disease. On a purely financial cost basis the loss of a husband during their working life in many cases can cause higher use of social care and the associated costs to the social services. From my own experience early knowledge of my condition means that I can continue with my life knowing that I am being monitored and that if and when treatment is required it can be provided in the correct form and at the right moment for me. Better to be aware of the problem and to be in control and able to respond in a timely manner. Alternatives comment: Improve the existing test, as the current test told me for years that I was OK.Organised official screening calling for attendance.Educate the male population that they are under threat and a clearer explanation of the simplicity of the procedure.

	Other comments: I feel I am proof that early diagnosis is the key both to helping our NHS cope and to helping the patient mentally cope with the diagnosis which can be treated rather than being told at a later stage when the outcome may be less favourable.
P569	Affected Comment: I know someone that has been affected by Prostate Cancer Evidence Comment: unsure Discussion comment: no Recommendation comment: Should be recommended, it could be missed otherwise. Alternatives comment: unsure Other comments: no

P571	Affected Comment: I was diagnosed with T3b from a random blood test. There was no screening, pure chance. I was lucky, if it hadn't been caught I would be dead by now. I think we should be calling men over 50 in to be tested, awareness raised & lives saved. I'm hopefully ok after ***** years but not out of the woods yet. Too many men just won't go to their GP. Evidence Comment: I think patient evidence was not fully reviewed. Too many men slip thru the net. Screening would save lives. I think the review was biased towards saving money and not lives. I've had a ***** who had elevated PSA levels, had the MRI, had the biopsy & not much found. He didn't mind. Yes that had a cost but he's relieved he's not one of the "one in eight" men. Discussion comment: I think the public & professional outcry over the findings/conclusions plus the huge petition, shoes how wrong the conclusions are. Recommendation comment: Screening should be recommended along with campaigns to raise awareness and every GP surgery should contact all men over 50 to invite them in. Alternatives comment: Raising awareness Every man over 50 plus those more at risk should be contacted & invited in to discuss their options. Other comments: Involve patients, charities and professionals.
P572	Affected Comment: As a person of ***** yrs with a number of retired ***** colleagues who have been diagnosed with prostate problems I believe that National screening is a necessary action. Recently it was agreed that bowel screening would be taken up by the NHS in England. We in Wales have had this for years with excellent results, I personally am thankful for this having recently been diagnosed and currently having treatment. I would like to know if the proposed prostate

	screening would include the Welsh Health Service as we tend to be omitted due to devolution in many consultations
P573	Affected Comment: I'm a Testicular Cancer survivor and ***** years later am still living with the after-effects of my treatment. Earlier diagnosis would certainly have made life so much easier (and cheaper for the NHS). When presented for treatment my prognosis was "less than ***** months to live" and after ***** months of heavy-duty chemotherapy I'm thankfully still here. In the space of one months my cancer numbers had more than quadrupled – earlier diagnosis could have required simple 40-minute surgery to remove the cancerous testicle and follow-up monitoring... very considerably cheaper for the NHS than ***** months of expensive chemo. Recommendation comment: Screening saves lives... simple! Early diagnosis generally means much less treatment to achieve a cure and with the NHS under financial difficulty it makes sense to diagnose early and thus save the NHS precious resources that otherwise expensive and often prolonged treatment would have ensued.
P574	Affected Comment: My husband had a prostatectomy in *****. At every stage of diagnosis and treatment he was reassured that the cancer would be eradicated, but he now has stage ***** prostate cancer. In ***** he was ***** and had never been screened for prostate cancer despite having prostate cancer in the family. He had to ask his GP for a PSA test, not the other way round. We were amazed that this test is not routinely offered to men over 50. Evidence Comment: I think some of the evidence feels disconnected from real life. I think the harms of late diagnosis are underplayed. I don't think the impact on high risk groups and inequalities has fully been recognised by the review. Discussion comment: I think the conclusions feel overly cautious. I was surprised and concerned that screening has been rejected especially as there is evidence of rising diagnoses, late stage presentations and inequalities. Recommendation comment: I think that targeted or risk-based screening is a sensible first step. I think that men at higher risk deserve earlier assessment and clearer pathways. I understand concerns about overdiagnosis or overtreatment, but I believe these can be managed in a modern health service.

	Alternatives comment: I think there should be organised prostate cancer testing, instead of the current ad hoc system. There should be earlier risk assessment for higher risk men, and clearer access to PSA testing. There should be better GP support and education, improved public information, and action to tackle inequalities in access and outcomes. Other comments: I think there is a need to keep policy under ACTIVE review as new evidence emerges. I don't think there should be a wait time of every 2,3 or 5 years to re-review policy. I think it is important to involve patients and communities in future decisions. I want to highlight the need for urgency as well as the requirement for evidence led policy. Whilst screening decisions are complex, I would like lived experience to be considered alongside clinical evidence. In my case, my husband may have benefitted significantly by having routine screening before the age of *****.
P575	Recommendation comment: Recommended. One life lost is one too many.
P576	Affected Comment: Yes, I am a survivor of prostate cancer but my screening was later in my life and my cancer had spread locally. I was in full time employment at the time but due to the scope and severity of the treat I never returned to full time employment, ending my ***** career earlier than I had intended. This has impacted on my financial situation, impacting on my wife and family. Evidence Comment: My screening was in response to my concerns due to urinary symptoms which had been going on for some time. I feel that had I have been offered a blood test earlier my condition would not have been so severe. At diagnosis my PSA was ***** and my Gleason score was *****. Discussion comment: I am surprised and concerned that the recommendations did not go far enough. Catching the condition early would have made a huge difference to my treatment. Due to the cancer having spread some treatment routes were no longer available to me, meaning it may return in the future. Recommendation comment: Screening such be offered to catch the problem much earlier. A simple blood test saved my life but had I had it sooner the cancer may have been much less severe and might not have cost me my career. Alternatives comment:

	Proactive intervention at an early point in my life would have been helpful. Both my sons are now better prepared but this only because of my experiences. Other comments: Provide screening early and more regularly to catch the disease early. This will save lives and cost less in the long run.
P577	Affected Comment: Some time ago I consulted my GP about what I thought was an abcess in my groin. This was the case but my GP also gave me a thorough health check which included a PSA test leading to my prostate cancer being diagnosed and treated with surgery, radiotherapy and intermittent hormone therapy. Since the cessation of my treatment 3 years ago my PSA results have been normal. Had it not been for this test which was random I probably wouldn't be here now.
P578	Affected Comment: At diagnosis I was told that I had stage *****, metastatic prostate cancer which could not be cured and that I would have ***** years to live. Evidence Comment: The conclusions and answers are to the wrong question. Screening does not over treat patients surgeons do. Discussion comment: The report focuses on over treatment of some patients and blames this on screening. Logically the over treatment is the fault of the surgeons reviewing and offering treatment to the patient. So it's the surgeons that need proper training, not denying screening to all men. Recommendation comment: Too many men, like me, are given a death sentence because we are not screened for prostate cancer, catching the disease at a stage when it can be treated. Alternatives comment:

	Keep researching new methods to refine the screening process. Other comments: Its not until you sit in front of a surgeon that tells you you have an untreatable prostate cancer diagnosis and that you have three years to live that you realise how important it is that we catch the cancer at its early stage. This would be where screening would help. It might not be perfect, but for those men who die because they didn't know they had prostate cancer it sure feels like a better option to screen than to say it isn't perfect so we won't do it.
P579	Affected Comment: My dad was diagnosed with prostate cancer at *****, my younger brother has a swollen prostrate st ***** and I have had a swollen prostrate since ***** and I'm now *****. Evidence Comment: Not enough importance placed on high risk men like myself and my brother. Both over ***** both got enlarged prostate our dad had prostate cancer, I'd like to know why we're it screened twice yearly ? Discussion comment: Please rethink the decision to not have a national screening scheme especially for those at high risk ? It seems to me that it's a financial decision over a moral or ethical one ! Recommendation comment: Yes absolutely, catching this early is the key ! Women get screened for both breast and cervical cancer, why don't men seem to matter as much, or that's how it feels ? I find it hard to believe that it's not already been decided to go ahead and screen high risk men and hopefully get the early diagnosis that are so important with any cancer ? Alternatives comment: Send high risk groups free self test kits for the PSA twice yearly would be a start ? Soft tissue scans once a year ? Other comments: The lack of interest from the government or the health service is astonishing considering the amount of tv and social media air time this disease gets from celebrities and low public alike. The answer is easy, cost shouldn't be a factor, introduce a screening program as soon as possible, please ?

P580	Affected Comment: I was diagnosed with Prostate Cancer almost ***** years ago now. By the time I realised something was wrong it was too late. My psa was *****. Its been devastating for the family. I had to retire causing financial hardship. Such upset for the sake of a blood test. My Doctors surgery had no information on display regarding prostate cancer. Never mentioned in well man review at 65. .. Evidence Comment: I cannot understand why so many men have to beg for a psa test. I believe some doctors are reticent to offer psa tests as the cost is suffered by the surgery budget. Discussion comment: It a total mess in opinion. The NHS guidelines are pathetic and outdated. I felt hoodwinked when I realised a blood test was available. A shrug of the Doctors shoulders and sorry you'll probably die. The treatment is brutal but early intervention is crucial. Recommendation comment: Absolutely. Screening would save 12,000 lives a year. Caught early it's curable. But more importantly it would stop many men like me feeling totally inadequate sexually and the treatment if earlier would have been kinder to me and much cheaper to the nhs. Alternatives comment: Nationwide Advertising especially in surgeries. I literally had to beg them to put up a poster on Prostate Cancer in the surgery. Other comments: Why don't the screening committee take evidence from people in this storm. I offered a few months ago to go along and speak to them. How can a bunch of women in the main have any compression of how it makes a man feel. I have never forgotten then smell of fear when I arrived at my first Urology clinic. Seeing a bunch of broken men awaiting their turn. IT IS UTTERLY DEVASTATING AND NOTHING SEEMS TO CHANGE. THANK GOD FOR CHRIS HOY AND OTHERS FOR TRYING TO GET SOME SENSE TO PREVAIL.
P581	Affected Comment: My husband died from Prostate Cancer Recommendation comment: Screening should be recommended:my husband would have received a diagnosis when it was in the early stages,but he had no symptoms and was diagnosed with Stage 4..he could have been saved if he had been screened

	Other comments: Listen to the families who have listened to their loved ones
P582	Affected Comment: I was offered a test by my GP aged *****, though I had no symptoms. The results were Stage ***** / terminal cancer. If there was a screening programme in place, my cancer could have been caught before it was terminal. Evidence Comment: As above; I was offered a test by my GP, though I had no symptoms. The results were Stage ***** / terminal cancer age *****. If there was a screening programme in place, my cancer could have been caught before it was terminal. Discussion comment: Screening has to happen to avoid unnecessary deaths of men. I'm Stage ***** without symptoms with no hope of being cured age *****. Because of no routine screening programme, I am under a death sentence, with a vague time frame of some years (single digits). Recommendation comment: Screening should be recommended. Men shouldn't accidentally find out they have Stage ***** / terminal cancer. Alternatives comment: There isn't one, screen men as you do with women and breast cancer. Other comments: Routinely screen men over 55 years old every 3 years.
P583	Affected Comment: Currently trying to get diagnosis and fighting the bias of our GPs

P584	Affected Comment: It certainly did. I was diagnosed in ***** and treated over ***** by radiotherapy. I feel I am only now beginning to explore new matters and be invigorated about life again. This has made me a bit of a hermit, coming out of my shell. Tough on my wife, less keeping in touch with my children, reluctant to plan going too far afield. Now just starting to book trips and live a little more. Going on a ***** class tonight- the first one with my wife. Evidence Comment: I am not an expert in these matters, but we have to turn the Great Ship NHS from being a centre for treatment to a centre for prevention and treatment. Why if all women can have breast screening, can't all men be treated for prostate cancer? I know there are false readings, but there are in breast screening until it becomes better as it is today. Discussion comment: The conclusion is short sighted and fails to take a simple test to support so many men. Recommendation comment: It is important to screen to prevent for the health of the male nation rather than wait and have to treat the male nation. So many still do not know it is hereditary Alternatives comment: There could but screening is effective. It is done for bowel cancer for all of an age, women of all ages so why not men from certain ages? Other comments: Just get on and start screening rather than wimping about with half measures.
P585	Affected Comment: I have prostate cancer. Recommendation comment: Should be recommended.

P586	Affected Comment: I had/have prostate cancer, being diagnosed in ***** after being refused a test twice by a female doctor, a male doctor agreed with my concerns. I received ***** sessions of radiotherapy and ***** years of testosterone suppression. I was lucky as my cancer was just starting to escape from my prostate. Despite my telling every male I met to demand a test, within 2 yrs two friends who hid from their symptoms were diagnosed. One died within 9 months of diagnosis, one is in the terminal stages. Evidence Comment: It is the male equivalent of breast cancer years ago, ladies hid from their symptoms and problems they had for fear of treatment or embarrassment. These barriers have to be overcome in men, and national screening will help with this, the macho bravado will be overcome as more men get tested and it becomes the norm. Discussion comment: It is the male equivalent of breast cancer years ago, ladies hid from their symptoms and problems they had for fear of treatment or embarrassment. These barriers have to be overcome in men, and national screening will help with this, the macho bravado will be overcome as more men get tested and it becomes the norm. Recommendation comment: To reduce the needless deaths of men, surely early diagnosis and treatment is cheaper and preferable to a long terminal period with treatment and the included costs of hospice care. Recommend screening. Alternatives comment: Without screening how would they know who had "This condition" to offer the "Many alternatives"? Other comments: Screen, screen,screen!
P587	Affected Comment: At ***** years old, last year I requested a PSA test. After ***** months of tests I was diagnosed with PSA test. Thankfully I am able to have treatment which will hopefully get rid of the cancer. Had I waited until I was 70 however, my PSA score would have been slightly within the higher guidelines for that age and as such, I would not have been referred for treatment and by the time I got a further test it may have been too late. Recommendation comment:

	It should. Prostrate cancer is a massive killer for men but if caught earlier it can be cured or at least treatment can extend your life.
P588	Affected Comment: I currently have Prostate cancer Recommendation comment: Yes screening option for everyone over the age of 50. I tried to have a PSA test at my surgery but was fobbed off but I tried again a few months later and managed to book a test which came back positive. I am now waiting for surgery. All the adverts regarding Prostate cancer get checked but then its like a door that you cant open to get a test Alternatives comment: For me it was a blood test but I do believe other methods are been evaluated Other comments: If there is no national screening programme at least let the people that do want to get tested, be tested.
P589	Affected Comment: I was diagnosed with prostate cancer in ***** after a mri biopsy and bone scan. I first asked for a psa test in ***** but was told by my gp surgery no we don't do them you will have other symptoms. I had no symptoms whatsoever in ***** I insisted on a test I then received a phone call from a doctor in the surgery who asked a few questions then said you have cancer I had not had any tests. Eventually in ***** I was diagnosed with prostate cancer I underwent radio therapy for ***** days I am now in remission so if had left it to my gp surgery I dread to think where I would think where I would be now Evidence Comment: I don't think they were serious in their review they did not seem to care Discussion comment: No Recommendation comment: Yes screening is important as my case proves

	Alternatives comment: What alternatives Other comments: No
P590	Affected Comment: I was diagnosed with Advanced Localised Prostate Cancer in ***** at the age of *****. The cancer had extended beyond my prostate by the time it was found. At that time I was in perfect health with no symptoms of any problem with my prostate. My GP found the tumour during a digital examination when I attended his clinic with hemorrhoids. I consider myself very blessed to have found the tumour and have it treated but sad that my health outcomes would have been very much better if I could have been screened at an earlier stage when the cancer was not so developed. I am also sad that other men in my situation, in the absence of screening, will not be so fortunate. Evidence Comment: My PSA was ***** (at age *****) by the time the tumour was discovered. A routine PSA test for screening would have been potentially life saving for me. With good PSA diagnostic advice backed by existing data I would have been able to monitor changes and have a biopsy only when needed. But this would have allowed me to be treated before the tumour spread outside the prostate. Avoiding screening purely to avoid unnecessary treatment has resulted in a life changing condition for me. Discussion comment: It can only be a good thing that men with genetic predisposition are getting PSA screening. My view based on my own experience is that this does not go far enough and that all men above a certain age, say 60, should be screened. I am advising all of my friends to seek a test and I am sure that the current publicity is prompting many men to do this anyway. Recommendation comment: My regret is that I did not seek an earlier PSA test citing changes in my urinary habits. But without screening I was ignorant that these changes meant something. I would urge the review to introduce screening and believe that this would save and improve many lives immeasurably. Alternatives comment: There are more accurate tests than the basic PSA already available in the United States. The Prostate Cancer UK Transform trial should be a major priority for funding in the NHS. Prostate

	Cancer Research has a project running with Cambridge University to develop a similar accurate test. I believe that with the right prioritisation and appropriate resources we can improve our ability to screen with an accurate test within a short time. Other comments: GPs should be given a clear directive to advise PSA testing to any patient when they consider there is a need.
P591	Affected Comment: I have been through a horrendous time with the illness of Prostrate Cancer. The capability of our NHS to assist me in my fight against this harrowing condition filled me with so much pride and faith in our country. My family did help so much, I will be forever grateful for their understanding of the Cancer condition and their support. I have a incontinence condition, from the Radiation damage used in the cure of Prostrate Cancer and a failed procedure removeing a catheter. I am still breathing, walking and talking for which I am so very grateful. My social life came to a complete abrupt end due to my condition and the complications and mistakes in my NHS care. My friends are full of understanding and sympathy. I had a very fulfilling social life with my friends. This was very important to me and my partner. The loss of this important relief and mental wellbeing can not measured, but I am suffering with this mental complication in my life now. Stress, loss of confidence and general weakness in my mental state are a large part of my life now. Evidence Comment: I have tried to record my Cancer experience above. As said, I am so grateful to survive. My plea to the UK NSC committee is to look at and ask if the evidence for the support or not to support, is truthful, relevant and above all honest in it's presentation, Discussion comment: The UK NSC has to look more closely at the evidence and comments associated with the evidence presented to the inquiry.

	Recommendation comment: There is no doubt in my mind or the tens of thousands of Prostrate Cancer suffers, survivors and unfortunately those who did not survive, a massive need for a complete screening regime, fully funded on the NHS. Are men now second class citizens? This screening programme is long overdue. The importance of the programme to protect, give hope and confidence to men can not shouted loudly enough. The Screening Programme sould, most definitely be given the green light. Alternatives comment: The screening programme is a nessasary important part of a modern NHS approach to modern diagnostic medicinal procedures. The so simple blood test is now more reliable, accurate, nessasary and effective as a medical tool for NHS. Other comments: The improvement of our NHS is vital. There will be advances in medical knowledge as time goes on. Hopefully as a country we will embrace and fund these improvements.
P592	Affected Comment: Yes,my beloved partner ***** was diagnosed with Prostate Cancer at age ***** after having gone to PSA testing event run by ***** in ***** – after being nagged to do so by myself. (***** had had “well man ” check at age ***** at local GP surgery in ***** but they failed to mention Prostate Cancer check completely.) His PSA was ***** so he was advised to take action -he was given various options - prostectomy,radiotherapy,not advised to go for active surveillance though. ***** was educated man,had degree, however no medical knowledge and as with most men very rarely saw his GP, he also was ***** - very keen ***** and was scared that surgery would affect quality of life /his hobby as well as erectile dysfunction etc so sought another option – HIFU -which was under clinical trial conditions. Long story short he had HIFU at ***** hospital but it failed. After ***** died ***** his consultant wrote to me saying that he thought the disease had already got hold of him before HIFU op done. ***** suffered nightmare of living with advanced PC for ***** years.I was his carer and did all I could with help from local ***** hospice at end. If there had been a proper screening service,also proper advice for ***** at original diagnosis (they told him he needed “radical treatment” do you know he didn’t even realise what “radical” meant in medical terms. Evidence Comment: As I recall the opinion of the committee was that screening should only be done for men with Brca gene. They seem to ignore the fact that Brca gene checks are only done on men with PC when everything else fails -well that was our experience.

	Our oncologist at ***** purely gave the “menu” of treatments -prostat,radiotherapy,chemo before at our insistence trying Brca check in case ***** could have Olparib -but no Brca gene in ***** case. Discussion comment: Please see above comments Recommendation comment: If screening had been done in ***** case at 50yrs – he would more than likely be alive today. I strongly recommend that screening be done. Alternatives comment: Educate GPs to know more about Prostate Cancer. PC in many cases has no symptoms at early stage -its only when it gets to Advanced stage that symptoms appear. I have listened and read over the last 5-6 years of so many instances of GPs refusing to test men and only when it's too late – just because they think it will cause more problems by testing. Do you know so many lives lost -12000 men die every year from this disease it's beyond belief – anything,absolutely anything that can be done should be done!!! Other comments: In ***** experience it would have been so much better if he had been able to discuss the pros and cons of each treatment -surgery,radiotherapy etc right at the beginning,instead he did his own research which unfortunately led to us taking wrong path. Please,please realise the terrible toll this disease has on the men in this country and the poor widows,family left behind.
P593	Affected Comment: I am lucky. My GP surgery will include a PSA test in my yearly bloods tests. I know that the PSA test has limited accuracy and repeatability but its all we have at present. Two of my friends have had prostate cancer. One has had life changing surgery, but he is alive, and ONE OF THEM IS DEAD. Prostate cancer is now the No.1 cancer killer in the UK. It is grossly unfair and unreasonable that men, particularly those in high risk groups cannot be offered a national screening test. I believe that the inequity with women who are routinely offered breast and cervical cancer screening IS AN OUTRAGE and symptomatic of a culture where men are regarded as second class citizens. Discussion comment: I feel that the review has entirely missed the point. The test has deficiencies. We know that. However, I believe that I have minimised the deficiencies in my own case by having a PSA test every year. By doing so I have built up a record of results that are reasonably consistent. So, now, I can tell if a test is out of range for me. Clearly, one test taken in isolation could produce

	an unreliable result but 6 or 7 tests creates a set of results where individual tests have less weight and noise due to errors is reduced. Why was this not considered by the panel? Recommendation comment: Yes, screening should be recommended, particularly for high risk groups. Apart from the impact on individuals and their families of terrible prognoses arriving 'out of the blue' prevention is ALWAYS cheaper than cure. Alternatives comment: More information couldn't harm but I don't see any alternative to screening and it is disgraceful that the principle of a screening programme has been rejected.
P594	Affected Comment: I was diagnosed with Prostate cancer in ***** and had a radical prostatectomy in *****. I had no symptoms and it was discovered after a blood test for ***** showed up a raised PSA level. Since then I have become aware of many men that I know who have had/got PC and I would now describe PC as a kind of 'mini epidemic'. Relatives of a couple of close friends have had it too. As far as any of my family are aware I am the first recorded case in my family. I was ***** years old when diagnosed and I am determined to ensure my son and all men are able to benefit from early screening as a matter of course. Evidence Comment: I don't think anything was missed particularly but if there is the slightest CHANCE that cancer could be missed that must surely be good enough to merit a screening program. Since ***** I have had the comfort of knowing that I can rely on my annual PSA test, but why should men have to wait until they have had PC to then be tested annually? This doesn't make sense and feels like closing the stable door after the horse has bolted. Discussion comment: A national screening program should be introduced immediately (similar to the bowel screening program), what is there to lose? I received my bowel screening test kit this week) and will definitely send off my poo sample asap. I can choose to opt out of testing so I guess men have a choice, but at least the kit drops through the letterbox. Recommendation comment: It definitely SHOULD BE recommended asap, it will save lives. Alternatives comment: Strange question, surely screening is pre-cancer but 'condition' is at diagnosis of cancer so I don't know how to answer this, sorry. Other comments:

	Use sms's to alert men around their 50th birthday that if they haven't already done it then get a PSA test, it may be the best birthday present they'll ever get. I work in advertising, I've got a ready-made campaign set to go.
P595	Affected Comment: My diagnosed and treatment for prostate cancer was swift and the treatment I received effective However the back up after treatment was very poor I would like to see testosterone tested before treatment starts to have an individual bench mark for every patient Mine is recovering very slowly leaving me with menopause systems
P596	Affected Comment: I was diagnosed with prostate cancer ***** years ago and have had radiotherapy and hormonal injections. Thankfully currently in remission, Discussion comment: Further investigation needs to be undertaken to ensure test results are far more accurate. Recommendation comment: Always yes but only with a reliable test Alternatives comment: More publicity perhaps but are some men oblivious to this ? Other comments: None at the moment

P597	Affected Comment: Yes it has affected myself and my family. I was diagnosed in *****. Recommendation comment: Screening is most important to identify prostate cancer early.
P598	Affected Comment: I was diagnosed in ***** and was a big shock to myself and my family I now help run a prostate cancer support group and the overwhelming opinion of the group if they had been screened earlier they would've been in a better position Evidence Comment: They don't take in to consideration the affects of cancer on people and their families if the screening saved one persons life it's worth it Recommendation comment: It definitely needs to happen as it would save lives Alternatives comment: More support and conversation about it Other comments: We are trying to run a community testing session funded by our group the government needs to help us with this
P599	Affected Comment: My father had aggressive prostate cancer that spread, by the time it was diagnosed it was too late as it had spread from the capsule. The treatment thaht followed was debilitating and in some cases painful, none of which may have been necessary if it had been caught earlier. I have also lost ***** friends to prostate cancer and but also know ***** who had it caught early and were treated succesfully to date. Having lost my ***** at the age of ***** to Breast Cancer and now rightly having a national screening programme in place, it terrifies me to think that this cancer is being ignored. Discussion comment: Whilst II can appreciate the significant financial burden a screening programme might inflict on an already overstretched health system, a cancer that, for the most part, shows no symptoms until it is already fairly established and has no visible symptoms, has no place in a rhetoric of budgets and workload considering the realtive ease with which it could be introduced and the devastating consequences of it being diagnosed too late.

	Recommendation comment: It should definitely be recommended. All the statistics point to an increase in diagnosed prostate cancer across the board and it is predicted to increase further and it is now the most common form of Cancer in the UK. Statistics also show that there is a significant risk increase when men reach the age of 50 peaking at around age 70-74 and it also the 3rd most common cause of cancer death in the UK (2021-2023) and the mortality rate has increased by 9.4% since the 1970's. How can something so prolific be left to a lottery of genetic predisposition if that predisposition is rarely known until you have developed the disease. This feels very much like purely an instant cost decision without considering the fuller cost consequences long term. Alternatives comment: I can't see an alternative and creating more than one would surely be more costly than a straightforward and direct programme.
P600	Affected Comment: My brother died of prostate cancer and I have been diagnosed with it. The latter only happened because I joined a screening programme in *****. A friend died of prostate cancer. Evidence Comment: It appears from a recent study that the economic basis of the review is flawed. Discussion comment: It is incontrovertible that thousands of lives would be saved by a national screening programme. Ethically, there is no argument. Furthermore the economic savings to the NHS and to the wider economy will be significant. The combined ethical and economic results make it a matter of extreme negligence not to introduce screening. Recommendation comment: It should be. See previous answer. Alternatives comment: There can be no comparable alternative. The argument that it might cause unnecessary interventions is spurious. There simply need to be stage checks at each step from screening result to scan, to biopsy, etc.

P601

Affected Comment:

I was diagnosed with high risk prostate cancer in ***** following a PSA check a couple of weeks earlier.

i had no symptoms and as i was going to the GP for a routine injection i met a couple whom i know, both quite distressed, on asking what was the matter he told me that he had just been diagnosed with advanced prostate cancer and the cancer had spread and could not be cured.

I continued to my GP appointment, asked for a PSA test which cam back at *****. when the consultant gave me the results (after more tests and byopsy etc) i asked what would have happened if i had waited 6 or 12 months. shes replied "we would be having a differnet conversation". this could have been picked up much earlier if regular PSA testing was available.

Evidence Comment:

i dont feel qualified to answer this one, however, i feel that my answer to No 1 above should be interpreted as a lay man's view of this question.

Discussion comment:

once again, i dont feel qualified to answer this, however, my person experinace is that regular testing is absolutly necessary in the hope of saving lives.

Recommendation comment:

screening, in my view, should most certainly be recommended for the reasons stated in my answer to No 1.

without the chance conversation which i had, my diagnoses would have gone from "High Risk" to "advnaced" and my life would have been in serious danger.

screening, on a reasonably regular basis, could have prevented this situation and saved the NHS the very expensive treatment that i am now receiving.

Alternatives comment:

i dont know the alternatives except a reasonable but high level public information policy could well help.

some years ago i was fortunate to survive a very serious case of Sepsis – prior to which i hardly knew what Sepsis was. NOW – "could it be Sepsis" notices seem to be everywhere.

perhaps "Could it be Prostate Cancer" notices should be as prevelant.

Other comments:

due to the mental shock if not the physical intrusion (manageable) of a Proste Cancer diagnosis it is essential that action on screening becomes an absolute essential priority for any Government.

P602	Affected Comment: At the moment just been told I have stage 4 prostate cancer. Recommendation comment: Screening should be automatic, but whether the NHS could afford the likely outcome of thousands of extra cancer cases which come to light ! Alternatives comment: All males who have blood tests are given the chance of PSA blood screening automatically.
P603	Affected Comment: I was diagnosed ***** years ago, aged *****. My ***** and ***** were both diagnosed prior to this, but I was unaware. I was diagnosed with locally advanced, but ***** years ago I had biochemical recurrence, and ***** years ago diagnosed with stage ***** metastatic prostate cancer. I am responding well to hormone treatment, but am aware that I am unusually fortunate. Had I had a PSA test earlier, the cancer would have been detected earlier, and there is a greater chance that I would not have progressed to stage 4 incurable condition that I have at the moment. Evidence Comment: I agree that a raised PSA is an imperfect flag. My understanding is that a pathway of PSA to DRE to multiparametric MRI to biopsies does now weed out those who do not need further treatment to a greater extent than shown in the evidence. I understand that on hearing the word 'cancer', many men may say "just take my prostate out", but this is up to the clinician to decide. There are eligibility conditions for most treatments; it is not all down to patient choice. I take issue with the calculation of 'unnecessarily treated'. How can you know that the treatment wasn't necessary? So there was no trace of cancer on a post mortem? Well that just shows how well the treatment worked. This could just be my lack of understanding, but it baffles just about everyone I talk to, so if this is going to be your argument, you probably need to explain it better. Discussion comment: Personally, had I been screened with a PSA test, I may not now have incurable cancer. I think it's unfair, but I am not angry about it; just sad. I appreciate you have to make decisions for a population, not an individual. I think the recommendation of screening men with the BRCA mutation is a bit bonkers. Are you going to genetically test everyone, to see if they are eligible for a PSA test? Will genetic testing be openly available to everyone? If not, then it's a cover up. Here's a cinema ticket, but I'm not going to give you the bus fare into town.

The recommendation is inconsistent with the programme offering genetic testing of the BRCA gene to grandchildren of Ashkenazyi Jews. My ***** children have all taken up this offer, I assume to identify their risk of prostate and breast cancer.

Recommendation comment:

To what extent should I expect the state to keep me alive? I suppose that's what you're all about. I am ***** years old, and think the men who complain about being diagnosed de novo stage 4 in their late seventies and eighties really have nothing to complain about.

I think those men currently thought to be at higher risk through ethnicity or family history should be screened. Why? Because lives will be saved. Life after and on prostate cancer treatment is miserable and expensive, but likely to be short. The earlier it can be caught, the cheaper it is to treat and the greater the chance of cure. But I would also restrict it to younger men, if money is tight, which of course it is.

Alternatives comment:

Changing our attitude to death as an inevitable part of life.

Insisting that patients being offered prostate cancer treatment talk to those who have been through it, or are living with it. Which means talking about death, sex, incontinence and manhood, none of which is easy or common.

There seems to be a lot of inconsistency between GPs as to whether requests for PSA tests or other screening methods are agreed to. That needs addressing.

You could have a mammoth awareness campaign, but that would be a bit odd if there wasn't a screening programme; so many prostate cancers have no symptoms.

Other comments:

I have read much in the press about the 'indignity' of a digital rectal examination and how we must find alternatives. For goodness sake, it's totally harmless, it's in the clinician's job description, and can be very useful. My GP was in there for microseconds and was able to tell me the very strong likelihood of bad news even before an MRI or a biopsy.

P604	Affected Comment: This condition, Prostate Cancer, has not affected me personally. I have had two PSA Tests (**** and ****) both of which had 'good' outcomes, thankfully. But, that said, I do understand the fear and reality of have cancer, when back in **** my GP, an Oncologist, and a Pathologist Report, told me I had Cancer of my ****. By the time I went to meet the Consultant ENT Surgeon, who was going to operate on me, the cancer had miraculously gone away. Fear of the unknown is somewhat unpleasant. Meanwhile, **** weeks ago, I met up with **** friends, **** and ****. Both announced that they Prostate Cancer. ****, is seeking a second opinion from a UK Urologist Consultant friend of his, since the **** Consultant said he will give him no choice but to have his prostate removed. Thinks could render him impotent at the age of ****.He is not a happy man. As for ****, His PSA readings have shot up, from the Datums established over recent annual PSA tests. Luckily the doctors say he's in the early stages. As for my neighbours.... **** of them have had Protsate Cancer. There is a lot of it about. Evidence Comment: No comment. Discussion comment: Whilst the PSA test is not very conclusive as to one having Prostate Cancer or not having it, it is, or can be, indicative of the propensity of a patient have the cancer. Given this, it is, in my humble opinion, a good indicator that a patient should undergo further clinical tests for the disease, whether this be an examination at ones GP practice or an MRI Scan followed by an appropriate Radiologist's report. Recommendation comment: I think that regular screening should be given ALL biological males, from the age of 40(to establish a Datum for the patient), and at regular intervals based upon family history and ethnicity etc. Alternatives comment: No comment. Other comments: No.

P605	Affected Comment: My brother has prostate cancer and regarding family history my mother died from breast cancer and my uncle suffered from prostate cancer. The lack of screening results in the distinct possibility that I or my other brother could have prostate cancer without being aware of it until it is too late to do anything about it. Evidence Comment: York Health Economics Consortium review not taken into account Discussion comment: The refusal of screening for prostate cancer even though it is now the biggest cause of death from cancer shows lack of concern for male health issues in the UK Recommendation comment: Yes screening is better than nothing which is currently the case v Alternatives comment: No screening is the most effective proposal to reduce premature male deaths in UK from prostate cancer. I live with the fear that I have prostate cancer considering family history and that absolutely no preventative action is being taken by UK Government and Health authorities. Other comments: None which is basically the same situation as the UK Government
P606	Affected Comment: I am a retired ***** nurse and treated cancer patients every work day. My brother also had prostate cancer which was picked up with another Urology issue he had. Recommendation comment: I definately think screening should be recommended to stop the unnecessary grade 4 tumours that would have been caught and treated successfully. My brother was diagnosed because he had difficulty passing urine at ***** and he was told that his psa was raised and he had ultra sound prostate biopsies and was informed he had prostate cancer. He had a radical prostatectomy and his consultant then informed my brother that the specimen margins were not clear and his psa was raising! He then had to have radiotherapy. If there had been a screening program he would have been treated sooner the tumour wouldn't have spread outside the capsule and he wouldn't have had to have radiotherapy.and live with the worry that the cancer could spread elsewhere!!

P607	Affected Comment: I have very recently been checked for prostate cancer and thankfully given the all clear. I have an enlarged prostate that is now being managed by my doctor. Had I not taken the initiative it could have been alot worse! Evidence Comment: The fact the evidence has been misinterpreted is rather scary and needs revisiting Recommendation comment: Screening should be recommended to all relevant males that this could affect. Alternatives comment: I'm not aware of any alternatives Other comments: No
P608	Affected Comment: I have had an aggressive prostate cancer & had to have my prostate removed in *****. Surgery has saved my life, but I am left with no sex life, which obviously affects my wife as well as me. I also have urinary incontinence & have to wear a pad to avoid wetting my clothes. It is extremely traumatic for me & for my family. My friends & family are all aware. I continue to have regular checks & blood tests. Men must have some way of having checks on their prostate soon enough to catch this disease in time to avoid losing their prostate to cancer & to stop it spreading elsewhere other body. Ask a prominent surgeon like ***** Background:- I discovered I had prostate cancer following a random psa test as part of a men's group event organised by a local charity on behalf Prostate Cancer uk. I received a positive result from my blood test with advice to contact my GP, who reluctantly referred me for further examination. The consultant I saw gave me a DRE & said he could feel my prostate had significant hardening & would arrange a biopsy without an Mri scan. Information from Prostate Cancer Uk said a MRI scan is vital, before a biopsy as scar tissue occurs, obscuring the Prostate once the biopsy is done.

	I-sought a second opinion privately where a scan was taken revealing ***** aggressive cancers within my prostate, confirmed by a biopsy.. My consultant ***** recommended surgery as the scan showed that the cancer was almost contained within the prostate. He performed a prostatectomy shortly afterwards. Analysis of my prostate showed *****% of the cancer was contained but leaving a couple of percent at the margin. I had other scans to check if it had spread around my body, and fortunately it seems ok. Recommendation comment: Screening is a must! Early detection is essential, I had no obvious symptoms, but the positive PSA test was indicative & the DRE test & MRI scan, confirmed it. Pay more attention to consultant surgeons like *****. He has written about it widely. Alternatives comment: Continued advertising to highlight symptoms even minor ones to men. Set up clinical centres to deal with the disease Other comments: Spend a n equivalent amount of the NHS budget on Prostate, to that spent on women' breast cancer.
P609	Affected Comment: Prostate Cancer has entered my life several times. I have lost ***** close friends to it and I was diagnosed myself ***** years ago. My ***** friends missed out on early diagnosis and by the time it was found it was too late for them, ***** passed away shortly after. I was fortunate to find out early which was purely by chance, I visited the doctor for something unrelated but she asked me if I had a PSA test recently, I hadn't so she referred me and subsequently found out I had it. Luckily I was able to have HIFU as it had not developed and spread outside of my Prostate. This early test possibly saved my life. Despite this early diagnosis it was still an extremely worrying and difficult time. The waiting between appointments were particularly anxious times, my wife found this particularly stressful. Evidence Comment: I think their conclusion that full screening could do more harm than good as people may be unnecessarily treated does not reflect my experience. I have another old school friend who has discovered he has the disease. This was not discovered early enough and has spread so he has had to undergo radiotherapy with all the associated long term effects.

	The relatively newly available HIFU treatment is far less intrusive and can be performed as an outpatient treatment but this can only be used if it has not spread outside the Prostate I believe, so early diagnosis is critical. In my case I have been fortunate to not have any significant side effects, this is often not the case with other forms of treatment that have to be used with later diagnosis. Discussion comment: From what I gather I do think the concerns for over treatment are over stressed. The route to treatment involves tests including biopsies, MRI and CT scans before treatment starts so by that time the extent of any cancer will be known and whether treatment is actually needed. A lot of results may just require future monitoring. It also makes you wonder it is just a cost cutting approach. Recommendation comment: I believe screening should be recommended, especially in groups who are more at risk. The process at the moment is not clear and can result late diagnosis which only increases the costs for the health service as well as lost income for those suffering. Alternatives comment: From my experience a better framework for GPs is needed, PSA testing should be organised so that it is not a lucky chance that you get a test or have to argue with the doctor that you would like a test as was the case with my brother. PSA Testing should be the first step, not the current physical examination which is rather unpleasant. It doesn't really reveal anything which was the case with me as they found nothing unusual. Other comments: I can only offer my view from personal experience but having gone through the various stages of diagnosis and treatment it seems to be that regular annual review of the policy is important. I consider myself very fortunate and feel very sorry for those that have not been so lucky with early diagnosis. There are new discoveries and methods of treatment being researched which can only improve the outcomes for a lot of men in future.
P610	Affected Comment: My father suffered from prostate cancer in later life so i have immediate concerns for myself and also for my son as he ages. Recommendation comment: Screening for breast cancer in women is accepted as being worthwhile and in saving lives. Prostate cancer has not had the same publicity as breast cancer and there is significant evidence that many lives could have been saved if screening for this condition was in place. Alternatives comment:

	By providing more detailed publicity and by having a dedicated programme focussed on the condition with readily available clinics.
P611	Affected Comment: Father died of prostate cancer, my Mother died of ovarian cancer therefore I am in a high risk group. Evidence Comment: I think the financial modelling was flawed. I also think that the response is overcautious. With more screening and early non-invasive interventions the risk of good far outweighs the risk of harm. Discussion comment: This should be an ongoing field of study. Recommendation comment: It should, as above I think the good outweighs the harm. Alternatives comment: Not aware of alternatives to screening? Other comments: Roll out screening to all men over 45 and lower for those with family histories.
P612	Affected Comment: I had prostate cancer in ***** and underwent a prostate ectomy in *****. ***** Hospital were great, both before, during and after my operation. However I had to beg for a PSA test at my GPs as they said it wasn't a very conclusive test. I heard about having a PSA test from our Local Radio station as their DJ had had prostate cancer and he said " Any man who has to urinate several times in the night should ask for a PSA test" That convinced me that I needed to be tested. Sure enough it probably saved my life. Evidence Comment: Men do not like to talk about this type of illness.

	Any easily available test would benefit a lot of men. I have told my ***** sons to insist on regular testing at their GPs and to tell their children (my male grandchildren) to do the same. Discussion comment: No. Recommendation comment: It should be recommended, for the above reasons I have stated above. Alternatives comment: Stick to a screening program. I told my friends about my experience and at least ***** found that they had a problem and underwent treatment. Other comments: No.
P613	I am ***** with advanced prostate cancer. I was diagnosed in ***** after I asked for a PSA test. I had no symptoms and no family history of the disease. I would have requested a PSA test in ***** as I had been asking them annually from my GP but due to COVID there was a shortage of blood vials so I decided to wait. My PSA in ***** had gone from ***** to ***** in ***** months and was way higher than it should have been. After MRI scans and biopsies cancer was found in my prostate and spine. I have had a negative brca test so the current proposals would not have picked me up. I am now relying on expensive hormone therapy to keep me alive with all the associated symptoms. I cannot understand the reluctance to offer men this simple PSA test that could have helped me and the ongoing NHS treatment I will require for as long as the hormones keep working. Please allow screening to men as they are being discriminated against when women get breast screening and cervical cancer screening as a matter of course.
P614	Affected Comment: I have prostate cancer Evidence Comment: n/a Discussion comment: n/a Recommendation comment: We need a screening program considering the advances that have been made with regards to MRI and how efficient and quick this process can be. Considering the fallout of discovering PC

	late or too late I imagine this would possibly save money and NHS resources in the long run. Any other course of action seems shortsighted. Alternatives comment: For GPs to be a lot more proactive by screening male patients when they come for a general consultation. I believe all men over 50 should be checked and this would set individual baselines for PSA levels for future reference. Other comments: There is a mindset amongst many men and one which I had and that is I'm not going to get cancer at least not until I'm a lot older. Yes I saw the Prostate Cancer UK ads but they didn't apply to me in my mind. I'm fit and healthy don't smoke, drink or take drugs so it's not going to happen to me. And boom at age ***** being told not only do I have PC but it could have spread and was high risk post RP since I had a PSA of *****! So messages via social media, billboards and TV are not going to reach people it's real input from GPs and hospitals that will.
P615	Affected Comment: I have been fortunately, diagnosed with Prostate cancer, I have received treatment, with a full course of Radiology treatment, Also a course of medications which I am continuing as directed. This was all highlighted in a blood sample test taken at my local medical practice. My blood tests now show the best level of PSA figures possible, showing cancer is only just at the lowest levels possible. It is totally unfair, on Men, if they are not tested for Prostate Cancer, yet Women are screened for breast Cancer. Simply, it is Prejudice, against Men, and therefore cannot be allowed! Evidence Comment: As stated before, the funding for the male screening, must be found, and the testing for all men established. TAKE THE MONEY FROM FOREIGN AID. Discussion comment: See comments above. Recommendation comment: See the comments above. Alternatives comment: As far as I am aware the blood testing option is the best means to do the testing of all males for this killer. Other comments:

	The funding for the testing of male blood to check for Cancer should be funded by stopping Foreign Aid, to Pakistan, or Afghanistan.
P616	Affected Comment: I was diagnosed with prostate cancer ***** years ago having no problems until then. I thought the best solution was to have it removed by keyhole surgery, which I did. It was removed and home in 24hrs. The surgeon told me I was very lucky because the cancer was very close to spreading to my spine. Evidence Comment: The small cost of checking all men on a regular basis would outweigh the cost of surgery and save lives. Discussion comment: Yes, have another discussion because the problem, distress, and deaths from prostate cancer is not going away. Recommendation comment: It's better to screen men on a regular basis and save as many lives as possible and stop a lot of family sorrow even if some diagnoses are wrong. Alternatives comment: Maybe a pill or some medication will be developed in the future by the NHS that can be given to men before the condition develops. Other comments: No sorry

P617	Affected Comment: it might have affected my brother very recently but happily it was not diagnosed as such Evidence Comment: not that my limited knowledge and understanding allow me to state Discussion comment: nil Recommendation comment: no – screening for PC is as important for men as breast screening is for women Alternatives comment: a comprehensive screening programme is surely the safest and most reliable method to check for PC Other comments: no
P618	Affected Comment: Yes it has affected many friends & some members of the family on my wife's side. Discussion comment: I was very sad to hear that there won't be screening for this most insidious cancer for which there are no symptoms. It seems to be totally against all logic. Recommendation comment: Yes. As above. I wrote to The Telegraph about this and received no reply. In ***** where I recently lived, there was an annual screening programme run by the local *****. It was so popular that men could be seen queuing outside the large ***** Hall for the psa test. The possible drawbacks of the test were made clear. Results came through in a few days. I personally know of at least three men whose cancer was caught at an early stage by this test. I'd recommend speaking to someone in ***** about this wonderful initiative. You might get a sense of how many lives have already been saved. Alternatives comment: Apparently there are no symptoms – there is talk of possible lower back pain, increased visits to the toilet but these are common problems for men anyway. Advice at the moment seems to be 'hope for the best'.

	My wife's nephew has lost his father and uncle to this disease but still isn't eligible for a regular psa test. That's totally unacceptable to me.
P619	Affected Comment: I have lost two brothers to prostate cancer one was only ***** and regular screening could well have helped detect his condition earlier.
P620	Affected Comment: My diagnoses of prostate cancer was as a result of having a PSA test. PSA tests are not accurate, but they are better than nothing. Recommendation comment: Screening should be recommended
P621	Affected Comment: I was diagnosed with prostate cancer lately in ***** but dud not start treatment until *****.i received hormone therapy followed by radiotherapy, which finished on *****. Thus, over ***** passed between diagnosis and the termination of treatment. This delay in receiving treatment caused considerable anxiety both for myself and my family. In particular, had more cancer progressed between diagnosis and the start of treatment. No further scans had been made so I was unclear whether I still had Grade 2 cancer, and had one of the tumours finally penetrative the capsule wall. When I finally received treatment I was more than happy with the process. However interminable long delays had been difficult to deal with. Evidence Comment: No Discussion comment: No Recommendation comment:

	I am of mixed opinion. My PSA score was never above ***** therefore unremarkable. It was only because I informed my GP of reduced flow that a digital rectal exam was carried out and revealed irregularities. PSA alone was not an indicator of prostate cancer. I think too many older men just accept that it takes much longer to urinate as a fact of life rather than it possibly indicating something more sinister. Alternatives comment: Much better education whether through advertising or via GP surgeries. It would be useful if GP's actually asked older men and men of at risk ethnicities, if they have any urologist symptoms rather waiting for patient reporting. This could be done via invitations to Well Man Clinics, or by enquiry at annual medication reviews. Other comments: No
P622	Affected Comment: Yes it has. I was diagnosed with Prostate Cancer following results of a PSA test. Had I not had the test when I did which allowed for early diagnosis then there is every possibility that my cancer would have progressed to a point that it would have spread well beyond my prostate. My Father had it and my Nephew has it. Evidence Comment: I have often heard and seen the opinions of doctors who on occasion try to put men off from having a PSA test with the – its not always accurate or gives false positives spiel. Every man that I know and I know quite a good number who has Prostate Cancer had screening. Discussion comment: Many men can afford to have a PSA blood test privately but many men can't There should be universal access. Recommendation comment: Yes I do. My personal experience and seeing so many other men that I know and met whose cancer was detected by screening leads me to believe that it is vital that screening be offered to every male over fifty years old. Alternatives comment: My one hundred per cent opinion is that screening should be offered and also that there should be more public information available to advise males over the age of 50 that it would be advisable to have a PSA test – annually.

	Other comments: Information and more information on a regular basis. Public advertisement on TV. Don't let the male population down.
P623	Affected Comment: Several friends have been diagnosed with Prostate cancer. One of those friends had his prostate removed suffering with some of the post op symptoms. Recommendation comment: I simply work on the principle of early identification of a problem is better than curing something that comes to light at too late a stage. Other comments: A simpler, more reliable test would be beneficial.
P624	Affected Comment: Yes. It affects myself. I also informed my son and ***** brother to suggest they had a test to rule out the possibility of them having the same, issue as it can be hereditary. I was diagnosed with this condition *****. I had been having symptoms fairly commonly known including more regular need to urinate during the night. Also a sudden need to urinate with no notice. Evidence Comment: Notes I disagree with the outcome of the review and that further consideration be made to investigate further. Discussion comment: Yes I believe further discussion is required in order to review the decisions taken. Recommendation comment:

	Yes I think regular screening should be offered to all men above the age of Sixty years of age as it has been proven that prostate cancer is the most common cause of death in males of a certain age and that this could hopefully be deterred by regular and appropriate screening. Alternatives comment: Close monitoring with regular PSA testing. Other comments: Perhaps a more extensive awareness program for all men above the age of 50 with information provided by the NHS via the patients GP surgery to inform the patient of the possible risks of prostate and information on how the patient can arrange to receive any tests in order to confirm or not on the possibility of actually having or, risk of getting, this type of cancer.
P625	Affected Comment: i have prostate cancer for *****. I am awaiting radiotherapy to start and am currently on hormone replacement therapy which has a number of unpleasant side effects, as will the radiotherapy when it eventually starts. I asked for a psa test over ***** years ago but was told by my medical centre that if i have no symptoms then there is no point as it is unreliable. If i had had a test then, we could of found it sooner and not had to have this radical treatment, which would have saved the NHS time and money. And it would have also been easier on myself. I strongly believe that a national screening programme would be beneficial to both the NHS and the public. Thank you. Evidence Comment: SEE ABOVE Discussion comment: It does not reflect the opinion of the public Recommendation comment: It should. See above reasons Alternatives comment: Definitely test at risk patients who have a family history..

	Other comments: If a man asks for a psa test, the answer should be YES.
P626	Affected Comment: My partner was diagnosed with Advanced Metastatic Prostate Cancer in *****. It does feel like the bottom has just fallen out of your world when you receive this news. A Gleeson score of *****. The Urology Consultant that was the bearer of the news I remember was amazing. He was empathetic, sorry, understanding, informative but also frustrated. Frustrated that he was having to give out similar news so very frequently. Frustrated that he had lost one of his own Urology colleagues very recently yo metastatic Prostate disease. After ***** diagnosis, we encouraged friends to be tested, knowing now that Prostate Cancer can be symptom free. Very shortly afterwards, ***** friends were diagnosed, one who had no symptoms, the other who did have symptoms but whose GP refused a PSA on ***** occasions before agreeing. His Gleeson score was a ***** also. Luckily...if that's the right word...for both of them, their cancer was retained within the Prostate and both underwent a TURP and subsequently all the post-op issues that accompany that. Life changing though maybe not life threatening. Evidence Comment: I think the very important evidence that was missed was evidence from patients and their families. We were never asked for our opinions though I did sign petitions c/o PCR. Evidence about the cost of the disease to the patient and their families. Not just financial cost though this is obviously relevant as the ability to work through surgery, chemotherapy, radiotherapy and side effects is most definitely affected to varying degrees. But the cost in terms of quality of life, family relationships, altered identity, reduced fitness, reduced strength, reduced motivation and drive that accompany hormone therapy. This is absolutely massive, I am witnessing it first hand and I don't believe that the UK NSC have any grasp on this. I would be interested to know on fact how many, if any of the male members of the UK NSC have any first hand experience of Prostate Cancer Discussion comment: The thing that mostly confuses me is the emphasis on false positives with the PSA blood test. I understand that the PSA can be elevated for lots of reasons, not just due to cancer within the Prostate. I understand that some men with a raised PSA will go on to have a biopsy that is

negative. I understand that for some men that may present an issue, that they may feel that biopsy was unnecessary, invasive, embarrassing even. I understand that there are risks to a biopsy as there are to any medical intervention. What I don't understand is why, like with so many other procedures and interventions, men can't just be given the knowledge about the disease, the facts, the figures, the statistics and the choice. The choice to be screened or not. I do not know how many men in the relevant age category would choose to be tested but I know that it wouldn't be 100%. Was this taken into consideration when the NSC did there review? Was the conclusion that it wasn't economically viable based on 100% uptake? Or 75%? Or less? What I also don't understand is how the psychological impact on a male patient of a negative 'unnecessary ' biopsy seems to be given more gravitas than the psychological impact on a male patient of a positive biopsy and a diagnosis of advanced metastatic Prostate cancer with a Gleeson score of *****. May I assure you, the psychological impact is not comparable.

The numbers being diagnosed are rising because we now know there is a genetic link so sons and brothers of patients are encouraged to be tested; because of awareness of friends, even celebrities who have been recently diagnosed. Let's just recognise that and go forward with it.

Recommendation comment:

I absolutely do.

Men in the relevant age group should be given the information about Prostate cancer, the incidence, symptoms, facts, figures, statistics.

They should be given the information about testing as is presently available, it's pros and cons, risks, failures and successes.

They should be given the information about what a positive diagnosis means, the different grades of the disease, local v metastatic.

They should be given the information about the treatment options for the different types of Prostate Cancer from 'watchful waiting' to aggressive chemotherapy or surgery.

Then they should be given the choice. The option to make an informed choice of being screened or not.

Why wait for the 'Gold Standard' of screening tool that isn't yet available when many lives could be maintained or saved by what we have available at present?

Alternatives comment:

A public information and awareness campaign would be so so useful.

Other comments:

Yes, please listen to the Scientists, the Specialists, the specific Charities and please place more emphasis on their findings and knowledge than you do on the economics.

Many thanks

Affected Comment:

My father was diagnosed with prostate cancer aged *****. He had none of the symptoms commonly associated with this disease. He wasn't frequently getting up to pee at night or going more often or having difficulty during the day. It was found whilst undergoing tests for something else-unfortunately I've no idea what that was and can't ask as both mum and dad have now passed. He had radiotherapy but the cancer returned ***** years later – in his spine. Back pain was the only symptom at this time. He lived for another ***** years, but the last ***** were just an existence. He had no quality of life at all. He was admitted to hospital where he remained for the last ***** weeks till he passed away.

Evidence Comment:

As things stand PSA tests are not given routinely. Despite telling my GP of my father's cancer and his consultant telling me that my dad's cancer maybe hereditary, I had to repeatedly ask to get a test. I appreciate that the test has limitations but it's the only thing available until you get symptoms. When first diagnosed, my dad's PSA was raised. Therefore I place a lot of faith that if I develop this disease, I too will have a raised level.

Discussion comment:

For people at higher risk of having prostate cancer, including those like my dad who had none of the common symptoms, I'd like to see a more robust screening (MRI?) from say 50 years of age.

Recommendation comment:

My understanding is that cancer is far easier to treat the earlier it's found. On that basis, especially for those men at higher risk, a physical screening process rather than a blood test should be routine.

Although my dad was not initially regarded as high risk I feel that my dad would have had a longer and more comfortable life had a better screening process been in place.

Alternatives comment:

I feel that GP's need more support and education so that they are more likely to offer blood tests,

Affected Comment:

My father (*****) had a long standing prostate cancer, along with colon cancer for which invasive surgery was required. I have had manual and PSA testing for prostate cancer on three occasions, but am aware there may be a predisposition to suffer from the disease in the future.

I believe, irrespective of age, anyone with a family history should have the benefit of regular testing available. Just because we may not be of an ethnic type and over a certain age, we should not be denied of testing to avoid detection too late. White, caucasian, over ***** years of age.

Evidence Comment:

I believe the groups considered was too narrow, and it is high time that men's health, particularly relating to cancers, received the same weight as does women's. It should not be restricted to certain ethnic groups, just because the statics identified that certain of them, have a higher incidence

in relation to prostate and other cancers.

All people, irrespective of age, ethnicity, or sex should be treated equally when it comes to health testing. In the long run this will benefit individuals, families, and costs of treatment.

Discussion comment:

The conclusions and recommendations are considered too narrow (probably to restrict initial cost) and this is not a satisfactory reason.

Recommendation comment:

It is recommended – see previous comments.

Even though the statement that the standard PSA test is not “fool proof” it is the best available indication until such time as testing procedures have been improved.

Ask Sir Chris Hoy and other high profile sufferers what they think of the present recommendations.

Alternatives comment:

A suitable continuous publicity campaign regarding symptoms and steps to request testing.

Other comments:

Treat men's health conditions as seriously as those suffered by women.

For years we appear to have been treated as the lesser important sex when it comes to health. Treat all people with the same respect, and not restrict checks for health conditions due to age, sex, or ethnic type. Apply the tenets of the NHS the way it was intended rather as it has become politically “adjusted”.

Affected Comment:

I have personally experienced prostate cancer, having been diagnosed in *****. Like Chris Hoy, I had no symptoms until a few weeks before I was diagnosed and that meant my cancer had spread widely to lymph nodes and spine, pelvis, femur, ribs. (PSA *****). Both my grandfather and my father had suffered hence I had requested a PSA test at my GP a year before but was declined saying no need as no evidence. I was given little hope and was told I might optimistically survive 12 months. This felt like a death sentence at ***** years old. As an ex ***** I was in the exceptional position of being able to understand the medical science so I researched and took further advice and opted for complex treatment at that time not available in the UK. I then spent most of ***** having chemotherapy and different forms of radiotherapy abroad. This obviously affected my family, my ability to work, make any long term plans, not to mention the economic effects. My brother has benefited from my experience as (partly due to my prompting) he has ***** seen a rise in his PSA on annual testing and has been treated promptly for early stage prostate cancer and is now in remission. The follow up in my case is quarterly PSA testing and even after all these years the anxiety levels increase as the test results are awaited. Life and plans are lived in quarterly intervals.

Evidence Comment:

I have not studied the terms of reference for the review and whilst I cannot comment in depth on the evidence presented, I can comment from my own perspective. My own sense is that had my case been picked up earlier I would be in the same position as my brother now. Whilst false positives may lead to unnecessary biopsies PSA supplemented by MRI as I understand it leaves much less room for error and unnecessary biopsies.

My limited research has shown that early stage prostate cancer can be successfully treated for in the region of £30,000. Late stage can cost £100,000 per year. I know my current treatment cost is of the order of ***** per year (now covered by insurance but originally self financed which is why I'm aware of the cost) plus monthly injections at about ***** per year (covered by NHS). So as I understand it, if more and more cases like mine are picked up later and later (according to some sources 10,000 at stage 4 in UK per year) then the NHS will need to find an extra £1bn per year to adequately treat them. If one then includes stage 3 cases that number is likely to increase significantly.

Discussion comment:

To summarise, based on the outline above, can the NHS afford not to screen?

Recommendation comment:

For the reasons outlined above I am firmly of the belief that screening should be recommended. The screening program can be rolled out to those considered at higher risk first and then. There are circumstances involving other diseases where there may be ethical considerations in deciding to screen or not screen but prostate cancer is very treatable for many, even up to stage 4 but the costs of doing so may not appear attractive at late stage. This introduces unacceptable inequities in the population between those who can afford to fund treatment themselves or via insurance and those whom the state may decline to fund due to inadequate provision in the budget.

Alternatives comment:

With no screening program the NHS will simply have to find additional funds to treat late stage cancer. Getting the right people screened early as a priority would help the NHS significantly and help to further target those most at risk by using that information to improve targeting.

Other comments:

The UK has its own position regarding screening which is different from other developed countries- the EU has shown PSA screening can reduce mortality by 13%. The US also uses PSA testing on a wide scale. Australia and New Zealand also use PSA. The UK can and should follow the example of its peers. There have been concerns about over-treatment of slow growing cancer but PSA supplemented by MRI should only progress to biopsy where there is a significant risk of missing a fast growing tumour. Then the options for treatment and associated risk can be fully discussed with the patient before a treatment path is agreed.

Affected Comment:

Yes. My ***** was diagnosed with advanced prostate cancer (aged *****) in *****. He died ***** years later from the cancer after a series of various treatment. At my wife's request, and not aware of any symptoms I took a PSA test which was about ***** and referred for further tests. I was aged *****. Following a biopsy and MRI scan I was diagnosed with local prostate cancer and put on active surveillance. My PSA tests increased and two subsequent sets of scans and biopsies showed increasing degree of cancer to Gleason score *****. So I was advised to consider treatment and opted for brachytherapy. This was done in *****. To date PSA tests show me as cancer free. I did have side effects from the treatment (most acute at ***** month point). {some mild symptoms were occurring before the treatment} These have largely resolved. They do not significantly affect what the activities I am able to undertake.

Evidence Comment:

The Infographic

The Infographic presents the outcomes of the modelling in an intelligible way. It lists the key assumptions used in the model and refers to the evidence sources for each one.

I have concerns about the evidence for two of these in particular; the lives saved from screening, and the degree overtreatment

Lives saved

Two sources for the lives saved in the modelling are referred to. One has data on lives saved after 15 years (previously after 10 years) and the other after 23 years. The data shows an increase in the lives saved (per numbers screened) over the longer time periods. The infographic suggests that both the 15 year and 23 year figures are used. Should the basis not be the figure for the longer monitoring period. Indeed should this not be increased further to reflect the likely outcome over the entire lifetimes of the population screened. { In the 15 year follow up study it is stated that only 23% of both the intervention and control groups had died.]

Overtreatment

A main reason for not recommending screening is the risk of overdiagnosis and overtreatment. These categories seem to be blurred in some of the presentation of the conclusions but there is an important distinction in assessing risk of harm. Blood tests, scans and biopsies do carry risks of harm and short and long term side effects but the evidence in the report suggests the risks from treatment are much greater.

The report suggests that overdiagnosis leads to a lot of overtreatment. The infographic indicates that of 28 diagnosed cases (from blood tests, scans and biopsies) that 12 will be overtreated while only 5 treated appropriately. This suggests that a man faced with advice that treatment is required has more than a two thirds chance of being treated unnecessarily. This seems implausible but, if true, is surely very worrying.

The Infographic does not give an explicit reference to any study that has assessed overtreatment. It states only that this is based on clinical expertise for the assumption that men diagnosed with Grade 2 cancers will be overtreated. If this is right than this seems flimsy evidence for a key assumption.

In what I read about the CAP trial, referenced at (5) to the Infographic, I could only find a brief description of the methodology. But it is stated that those in the intervention group who were diagnosed with prostate cancer were randomly allocated between active monitoring, and treatment options (surgery or radiotherapy). If this is done without any further clinical assessment does this not potentially lead, by design, to overtreatment in the intervention group?

Discussion comment:

I am concerned that the presentation of the results of the review (and the modelling in particular) make it very difficult for a lay person or a non-specialist decision maker to understand how the conclusions and recommendations are arrived at. The overall approach is well explained but which numbers and supporting evidence is critical to the conclusions is more difficult to understand.

Two particular issues are the use of QALYS; and what the evidence is for some of the most important assumptions underlying the conclusions as presented in the Infographic (see previous section for comments)

QALYS

QALYS are used here to measure both harms and benefits. While this is clearly sensible the results as presented do not distinguish and characterise the “losers” and “gainers”. Most of the harms appear to be caused by overdiagnosis and overtreatment of one set of men while the benefits derive from lives extended for another set of men. Now to give an extreme example it may be that 100 men have a 10% decrease in their QALY (due say to discomfort from biopsies) while 10 men have a 100% increase in their QALY (due to life saving treatment). The net QALY of benefit less harm would be zero. But it might be considered worthwhile to save the 10 lives even with the harms for the other 100.

It is impossible to see such potential trade-offs in the way the data is presented. If some disaggregation between benefits and harms was presented it would aid understanding and could better inform decisions.

[Where QALYs are used primarily to assess benefits for the purpose of cost-effectiveness as I imagine is the case for eg new cancer drugs then disaggregation may not be so important.]

Recommendation comment:

Until the evidence is more clearly presented and supported it is not possible to take a view

Other comments:

As commented above the way in which QALYs are used in evaluating options should be reviewed

P631	Affected Comment: friends Evidence Comment: no Discussion comment: noyes Recommendation comment: yes its such a problem,as you age it seems more necessary Alternatives comment: I have no idea Other comments: no
P632	Affected Comment: Yes, my father and brother Both died relatively young ***** and ***** respectively. My brother in particular suffered badly as he had bone secondaries and was unable to stand or walk as his vertebrae collapsed After original diagnosis of prostate cancer both lived ***** yrs. It was not a long term illness for them. Discussion comment: I would like to see screening offered to individuals thought to be at risk as based on current evidence. This would I think have included my brother when my father was diagnosed and although my brother may have gone on to have prostate cancer it may have been diagnosed and treated before secondaries occurred. Recommendation comment: Not wholesale screening but risk based screening based on evidence Alternatives comment: More information, better understanding of risks. More encouragement of relatively young men to seek regular health advice

	Utilise social media and sports heros or stars to talk about prostate cancer, it is not always a really older mans illness, my family proves that. Other comments: This may sound way out, but at the time of ***** was all placed under restrictions etc due to possible radiation Might it be worth screening all men who were ***** in the restricted areas. I've always had a nagging feeling that ***** , whilst caring for them at that time may have contributed to their subsequent diagnosis
P633	Affected Comment: Yes I'm in remission with Prostate cancer. I'm one of ***** boys, ***** of us have it and the last one is to be tested. We all concerned about the genetic component. Do my ***** nephews and nieces carry the gene ? Is there a likely effect of my nieces having breast cancer ? Discussion comment: Yes Prostate cancer doesn't exist in isolation. It has ramifications for the whole family. I believe that where it clearly exists in families, genetic testing should also be available Recommendation comment: Screening should definitely be recommended for the reasons above. Alternatives comment: When I was diagnosed I recommended that all my friends should have the PSA test. Despite being over 50 most of them were discouraged by GPs without further symptoms. This should not be happening. Genetic testing and early diagnosis will save the NHS money. A Radical Prostatectomy is a lot more expensive than early detection and screening.

P634	Affected Comment: I had prostate cancer diagnosed in ***** following which I had a radical prostatectomy in *****. My concern now is for my ***** sons and future son in law who is from black ethnicity. My diagnosis was from a scan following a trapped nerve in my back which reported an overfull bladder to testing my bladder function and therefrom to finding cancer on my prostate. A random route to finding the disease! Evidence Comment: It needs to include those who have a family history of prostate cancer like my sons and son-in-law, whose ethnicity suggests he is more likely to get prostate cancer Recommendation comment: It should read the above comments. Alternatives comment: Absolutely Other comments: Prevention is better than cure and may prevent more expensive operations down the line.
P635	Affected Comment: My husband has incurable prostate cancer. It was found when he asked for a test in his 60s. No family history and his ethnicity is white. He would be dead if he hadn't had the test. There should be a screening programme for prostate cancer for all men over 50 just as there is a breast cancer screening for women over 50. To exclude anyone with a family history of prostate cancer and black men from screening is madness. Recommendation comment: Screening should be available to any man but particularly those with a family history and black men who are at higher risk. ----- Affected Comment: My husband has incurable prostate cancer Evidence Comment: He was diagnosed in his 50s. A screening programme from age 50 would have caught his cancer earlier Discussion comment:

	Institute a screening programme for all men over the age of 50 immediately Recommendation comment: Yes it should be. The risks for black men are well known. How is anyone supposed to know about a gene mutation unless they are tested. GPS can be reluctant to give a test but it should be every man's right to have one. Alternatives comment: What are the alternatives? I have no idea
P636	Affected Comment: No it has not. Evidence Comment: I feel it is totally wrong to refuse to screen men. We women have access to screening for both cervical and breast cancer. I have sons, they have a right to the same care as my daughter. Discussion comment: I welcome the review and hope that finally men will be given parity in cancer screening Recommendation comment: It should definitely be recommended. It's very difficult to get men to confront these issues and general screening would in my opinion change mens attitude to health screening. It should become the norm. Alternatives comment: I think everything is being done, screening is the next sensible move. Other comments: If a man is required to have a blood test fof any medical reason checking the prostate should be included.

Affected Comment:

My maternal Grandfather died as a direct result of prostate cancer. Back in the early eighties, his condition was obviously well progressed as he died shortly after being diagnosed. I certainly had no idea about anything to do with the prostate, but after being tested myself for signs of prostate problems, I certainly am much more aware of things. I was checked out because I was experiencing hematospermia. I subsequently had a P.S.A. test, a Digital Rectal Examination, and then a rigid Cystoscopy. Fortunately, nothing untoward was found, and things had cleared on their own volition. As prostate cancer is so prevalent in any man, especially one who's father or brother has succumbed, and black men are particularly prone to this terrible disease. If most women are offered breast and cervical screening, (after a certain age) I put it to the Government to offer equal opportunities to us older blokes.

Evidence Comment:

I think the figures speak for themselves, and proof indeed of prostate cancer being the most common cause of death in British men. Proof is there also of early detection being absolutely paramount. I understand that some men die with prostate cancer, but if left too late, far too many die because of it. I also understand about unnecessary intervention and the devastating side effects of this, but as better and better ways of detection are used now, hopefully more men will be spared this. MRI scans may avoid unnecessary biopsies' and radical prostatectomies', but only if men at risk generally are able to be screened, not just a small group who have been told that they have certain gene variations.

Recommendation comment:

Screening should be available for a much larger proportion of men at risk. Otherwise, far too many will be diagnosed too late to save their lives. This is very annoying, because early detection means much more of a chance of survival. As Sir Chris Hoy will certainly testify, because his diagnosis came far too late, national screening of men at risk, should be implemented forthwith, and become as common place as screening for women is.

Alternatives comment:

I think that general awareness is much more common these days. This is no doubt because a lot of public figures have spoken out about prostate cancer, Sir Chris Hoy and Dermot Murnaghan to name but two.

Affected Comment:

Yes I was diagnosed with Prostate Cancer after I was referred by my GP following a blood test for an unrelated condition. The cancer was identified as aggressive and close to or at the boundary of my prostate. The consultant said I was lucky to have been diagnosed when I was as it was aggressive but has probably not spread to other organs. I have now had an urgent radical prostatectomy.

Evidence Comment:

I am not a technical person but the evidence seems rather academic and not reflective of the experience and feelings of ordinary people. The discovery of my aggressive prostate cancer has particularly affected my wife who has been very anxious about it.

Discussion comment:

I disagree strongly with the conclusions and recommendations. The approach seems excessively cautious. I have undergone an MRI Scan, a Biopsy and surgery. While some of the experiences have been perhaps unpleasant I have gladly accepted them in return for having the cancer diagnosed and treated.

Recommendation comment:

Yes screening SHOULD be recommended for all men over 45. My reasons are:

1. While the PSA test alone may be unreliable, initial MRI scans will screen out most false positives before an invasive biopsy is needed
2. The biopsy is quite bearable and less unpleasant than other common treatments eg a dental root canal treatment.
3. Lasting harm from biopsies is very rare.
4. Screening will save many men's lives.
5. The side effects of treatment are not as bad as thought. I have recovered 90% continence in 3 months through exercises. Although my sexual function has been affected by the operation, I would much rather accept that than risk suffering metastatic cancer and death.
6. In the long run screening will cost the NHS less than treatments required when undiagnosed prostate cancer has metastasised.

Alternatives comment:

In my opinion screening for ALL men over 45, say every 5 years, is essential. No alternative is remotely comparable.

Other comments:

Prostate cancer kills over ten thousand men a year. Metastatic cancer is horrible and causes the need for much more unpleasant treatments. It doesn't just affect costs or statistics, it affects them, their partners, wives, families and whole communities. Please please please reconsider and recommend screening for all men over 45.

P639	Affected Comment: I have had Advanced Prostate Cancer. At the moment the latest PSA results are listed as undetectable. Currently have ***** monthly blood tests and ***** monthly hormone injections I was lucky I saw signs and was completely shocked it was Grade ***** cancer. Was told another few months it would have spread quickly as Gleason score was *****. Said no point removing due to invasion in lymph nodes and seminal ducts. Plan is to have hormonal treatment to shrink the prostate and starve the testosterone. Chemo to kill the cancer cells being invasive and radiotherapy to kill the cancer in prostate. Absolutely confident nowhere else they say I am really fit and healthy. I was totally fine about it and up for the challenge and luckily survived Recommendation comment: Should be and doctors etc be more receptive to request for PSA tests. Should be compulsory from 50 onwards Alternatives comment: I have spoken at a sports convention and was shocked that men had same sort of symptoms and not got the test or were not aware. Awareness is rising but needs to more
P640	Affected Comment: I am currently a Prostate Cancer patient receiving no treatment other than being monitored by the Macmillan Nursing Team at ***** Hospital under what is known as 'Active Surveillance'. I am very grateful to have been diagnosed early. This would have been unlikely if I did not have a GP who insisted that I had regular six monthly PSA tests. Evidence Comment: I simply believe that the UK NSC has made a grave error. All men over the age of 40 should be entitled to and encouraged to have an annual PSA Test. Something an eminent Consultant Urologist recommended to me back in the 1990s. The test itself is inconclusive but it is still all that we have to alert medical professionals to a diagnosis of prostate cancer. I think it is naive to ignore this and recognise that such screening is the only one that is not readily available. Discussion comment: Please see above. I think it is essential that the NHS get a grip of this huge gap in the service it provides. After all, early diagnosis prevents huge emotional and physical suffering and of course from the NHS's perspective, reduces costs. Recommendation comment: As detailed above it should be recommended and readily available. It should also be widely publicised with a national NHS campaign.

	Alternatives comment: At this point the PSA Test is still the most reliable means of alerting medical professionals to the possibility of prostate cancer. Until something else reliably replaces the Test then screening is essential. Other comments: Nothing further to add to my earlier comments other than to thank the Macmillan Nursing Team....one that represents a well funded charity. I doubt very much that if left purely to the NHS, patients would receive the punctual and regular treatment that Macmillan is able to provide.
P641	Affected Comment: I was diagnosed with Prostate cancer ***** years ago following an infection. Until the pandemic I had been undertaking yearly PSA testing, this stopped during the pandemic. I believe if there had been regular screening my cancer would have been detected earlier. Evidence Comment: I believe not enough weight has been given to the developments in diagnostic and investigative techniques in recent years. I am a retired ***** and have been involved with the debate over the years. In particular the use of highly sophisticated MRI gives much more opportunity to identify which cancers need treatment and which don't. Discussion comment: I think there is now overwhelming evidence to introduce routine PSA screening. I think the review has failed to take account of the recent advances in the diagnosis, investigation and treatment of prostate cancer Recommendation comment: I support the introduction of routine screening Alternatives comment: I think there should be better follow up of patients who have been treated and better management of the side effects following treatment. Other comments: I think the time for prevarication is over. Routine PSA screening may not be perfect but I think it would go a long way to improving the early detection of the disease and more successful outcomes.

P642	Affected Comment: I have three friends who have been diagnosed with Prostate Cancer, two white and one black. Fortunately all have gone through treatment and are well. Two (white) did not talk about their symptoms. My black friend found out by accident through feeling tired when *****. If there was a national screening programme this could have been diagnosed earlier. Discussion comment: The greatest killer of women is breast cancer and for years they have had a national screening programme. Prostate cancer is the biggest killer in men and there is no national screening programme for men AND THERE SHOULD BE! Recommendation comment: See above Alternatives comment: There should be NO alternative to a national screening programme! Last year talking to the person who sits next to me at my ***** who happens to be from the same ***** told me that he had been to our ***** GP for a PSA test and that anyone can just walk in to the surgery for a PSA test. THIS WASN'T WIDELY KNOWN AND SHOULD BE MEN OF A CERTAIN DEMOGRAPHIC SHOULD BE MADE AWARE THROUGH THE SURGERY. Other comments: Our local ***** annually holds a PSA testing day when members and the general public can go and take advantage of the PSA testing sessions offered.
P643	Affected Comment: I was diagnosed with prostate cancer *****. At the time I had absolutely no symptoms, but had become aware of people diagnosed at stage 4, with spread outside the prostate. At diagnosis I was Gleeson ***** , stage ***** , having had an MRI scan & a biopsy. Talking to the consultants at ***** at the time it was inferred that if I had waited ***** months longer it would possibly have broken out of the prostate & be incurable. So I am very lucky that my medical centre had initially agreed to do a PSA test, with the result being *****. My family has no history of prostate cancer. I am now ***** years into treatment with Prostat 3 DCS & radiotherapy on the NHS, plus Abiraterone, which I am funding privately. I have monthly blood tests & the PSA has been at less than ***** for *****! I am physically active ***** & *****. My Abiraterone finishes at the end of ***** & the Prostat 3 DCS *****. At present my wife, myself & family are very positive & feel very lucky I was diagnosed at an early enough stage. Evidence Comment:

	I am amazed & disappointed that the review seems to have ignored all the evidence for early detection to save lives & save the NHS a large amount of money! The early detection & excellent advice was important in deciding the correct course of treatment for myself. Discussion comment: I am amazed at the conclusion, which seems to have totally ignored the evidence for early diagnosis & treatment. Instead focusing on bad outcomes, particularly from surgical interventions. Seemingly ignoring the large benefits of screening & early diagnosis Recommendation comment: I think screening definitely should be recommended, as per the evidence above. Saving lives & saving the NHS a large amount of money! Alternatives comment: Make it easier to get a prostate test at their local medical centre.
P644	Affected Comment: I am ***** yers old. I was diagnosed with stage ***** metastatic prostate cancer ***** years ago. If I had been screend the cancer would have been caught at an earlier stage. I would not be dieing and my family would not be going through this with me. Recommendation comment: YES of course I do. Men, Husbands, Fathers and Grandfathers matter just like Wives, Mothers and Grandmothers. There should be no gender inequality in the NHS. Other comments: Spend as much money on mens cancer care as you do on Womens.

I was diagnosed with Prostate Cancer in ***** aged *****. I am in a high-risk category as my father has Prostate Cancer. Notwithstanding this I had to fight all the way to even get a PSA check and was told at first intervention by a consultant urologist in the NHS 'why are you here, you don't have prostate cancer', which turned out to patently untrue and he had no other clinical evidence other than one PSA result. I took this at face value as it was what I wanted to hear, from an expert. A year passed by and I was not happy, so pushed and in the end had to go to private medicine to be treated seriously. I was diagnosed with Gleason Grade***** and therefore a low-risk cancer and can undertake 'active surveillance'. I did this and repeat biopsies confirmed the same grade, but the PSA was rising. I decided after ***** years to have a RALP and this was achieved successfully, with histology then declaring it was Gleason grade*****. During this time I reflected on the lottery that is the NHS current system and how if I had followed the initial advice I would not have bothered to follow-up and this could have had a very different outcome. I did not have a BRCA gene abnormality which I knew as my sister's cancer meant I was tested. Prostate cancer kills 12,000 men a year in the UK per year and only by helping men to confront their medical problems with a screening problem will see this number reduce by following the NHS 'gold standard' of parametric MRI and template biopsy.

Evidence Comment:

Men need early notification of prostate disease if they are to be given a chance of long lives. Only targeting gene deformity specific populations will not make any meaningful difference as the men who have undertaken these gene tests are in the medical loop and know and will be informed of the risk, many others will not know or be aware they have a BRCA gene problem and so will not present themselves for PSA tests. An important consideration in this is the efficacy of the PSA test and in my experience after having over ***** PSA blood tests not one clinician or nurse asked or advised that you need to present yourself without having aggravated the prostate with bike riding, or sexual activity 48 hours before the PSA test. This ill-informed attitude to the blood test, but simple to fix, could prove to be a very effective way to reduce PSA result volatility with corresponding impact on down-stream activities.

Discussion comment:

I was surprised by the lack of ambition in the review to make a real difference to men's health and the number 1 cancer for men in the UK. Whilst PSA is not perfect with careful use of the tool and robust checks to ensure the 48 hour guidance is observed it is the best tool available on the NHS today to signal a problem. By having a screening programme this will drive even faster the development of cost-effective testing methods of 'liquid biopsies' or equivalent blood-test definitive testing that the NHS can adopt. It is this dynamic that I feel is missing, the ambition to drive new affordable and effective mass testing methods so that PSA testing can be stopped. This is a lost opportunity.

Recommendation comment:

Screening should be recommended for families with a history in the male relations of prostate cancer or the female side of ovarian/breast cancer. The men deserve this call up, as the majority of men do not talk about their health and do not want to confront these issues, the need for the health service to assist with this inertia is imperative. With improved PSA testing protocol, see earlier answers, and highly qualified clinicians it is possible to test and manage patients concerns before biopsies are needed. PSA velocity, doubling time and PSA density are all useful tools for the consultant Urologist but in my experience not used consistently or robustly, often just using their experience or judgement with reviewing a result there and then and not using advanced calculation tools to help assist a recommendation. Building a robust digital

system to capture patients PSA results, MRI results and biopsy results nationally could represent a very effective prognostic risk calculation on live data and standardise the guidance for clinicians, but I have seen no mention of this approach to effectively digitally model the data for prognostic purposes.

Alternatives comment:

I would advocate better GP education, who still quote the line they are taught at medical school, 'prostate cancer is the one you die with and not from'. Also nurses and GP's to be very strict on PSA 48 hour prior testing protocols. The use of up to date digital databased clinical PSA calculations supported with MRI and biopsy data giving a fly-forward prediction of disease progression.

Other comments:

The science is progressing fast in the charity sector, but is slow to come to market, there has to be a reason to invest and accelerate clinical trials of new blood tests that render the PSA test obsolete. Make that reason to invest by launching a PSA screening programme for men with a family history of the disease and create a tension for delivery within the pharmaceutical companies to push hard for new methods. The policy should be kept always open ready to change and not rely on a window that could move/change based on national circumstances, government elections etc.

I have given myself the best chance I have to live a long and happy life, but this is only the case as I drove my case every step of the way and always asking 'why?', I made by consultants be accountable for everything they said to me and to explain and in the end if I had believed the data I would be still under 'active surveillance' but harbouring a nasty Gleason ***** disease that would spread. Under-treatment is a real risk as well and every life is an individual who has family and aspiration, to boil this down to x in 1000 will have this outcome and y in 1000 that outcome ignores the human side, that there are always exceptions. We can't do nothing because of these exceptions we have to embrace the challenge and push the medical industry to do better, an ambitious screening programme can do this and deliver one of the biggest changes to men's health there has ever been, carpe diem.

P646	Affected Comment: Prostate cancer is becoming one of the most common and most devastating cancers affecting men today, yet it remains dangerously under-talked about and under-diagnosed. When I was told in ***** that I had prostate cancer, it felt as though the ground had been pulled from beneath my feet. No matter how prepared you think you are, nothing can soften the shock of hearing those words. In that moment, your future, your family and your sense of safety are all thrown into question. Earlier that year, my body had been sending me clear warning signs. I was visiting the loo far more often than normal – day and night – and I knew deep down that something wasn't right. I did what we are encouraged to do: I went to my GP, I had urine tests taken and sent off for culture, and I chased for results when nothing came back. Despite multiple attempts to follow up, I never received those results. My PSA level was ***** , which reassured everyone involved that there was nothing to worry about. Yet my symptoms persisted, and my anxiety grew. I was fortunate enough to have private medical insurance, and I made the decision to use it. That decision almost certainly saved my life. Through private care I was given a digital rectal examination, followed by an MRI scan and then a biopsy. It was only through these more detailed investigations that the truth finally emerged – I had prostate cancer. When I was told, I was utterly devastated. I am a *****-year-old man, yet I cried when I heard the diagnosis, and I cried again when I had to tell my wife. In that moment I felt fear, disbelief and helplessness all at once. Cancer strips away your sense of control and forces you to confront your own mortality in a way nothing else does. What frightens me most is knowing that many men in this country do not have the option of private medical insurance. They rely entirely on a public system that is stretched, overburdened and often forced to rely on crude indicators like PSA levels alone. As my experience shows, a “normal” PSA does not always mean you are safe. Men can, and do, have aggressive prostate cancer even when their PSA appears reassuring. That is why I believe so strongly that a national prostate cancer screening programme is not just important – it is essential. Early detection saves lives. Proper screening using modern imaging and risk assessment could prevent thousands of men from being diagnosed too late, when treatment options are more limited and outcomes far worse. No man should have to rely on luck, private insurance or persistence to get a cancer diagnosis. We deserve a system that actively looks for this disease before it destroys lives. Prostate cancer screening must be implemented as a matter of urgency. Too many families have already paid the price for delay. Evidence Comment: I am responding from a patient perspective. From where I stand, the evidence considered by the UK NSC feels very disconnected from real life and from what actually happens to men in the health system. On paper, prostate cancer risk is often reduced to a PSA number, yet my own experience shows how dangerously misleading that can be. My PSA was ***** , yet I had cancer. The models and thresholds used in the evidence base do not reflect how men actually present, how symptoms are often dismissed, or how cancers are missed until they are more advanced. This creates a false sense of safety that is not borne out by reality.

The evidence also seems to underplay the harm of late diagnosis. It focuses heavily on the risks of overdiagnosis and overtreatment, but not enough on what happens when cancer is found too late – the more aggressive treatment, the higher chance of spread, the psychological trauma, and the lifelong impact on quality of life. For many men, the cost of missing cancer early is far greater than the risk of finding a cancer that might never have caused harm.

There is also little recognition of inequality. Men with private medical insurance, who can access MRI scans and biopsies more easily, are far more likely to be diagnosed early. Men relying solely on the NHS often face long waits, limited access to imaging, and over-reliance on PSA alone. This creates a two-tier system where early diagnosis depends more on financial means than on medical need. That reality is not reflected in the evidence being used.

High-risk groups are also not adequately considered. Black men, men with a family history, and older men are known to face higher risk, yet the current approach treats screening as if all men are the same. A one-size-fits-all evidence framework fails to capture the real danger faced by these groups.

Overall, the evidence used by the UK NSC seems to prioritise avoiding potential harm from screening over preventing the very real harm of missed or late diagnoses. From a patient's point of view, this balance feels wrong. The human cost of delayed diagnosis – fear, suffering, advanced disease, and avoidable deaths – is not given enough weight.

Prostate cancer is not rare, not trivial, and not something that should be left to chance. The evidence base must reflect the lived reality of men, not just abstract models.

Discussion comment:

From a patient perspective, the discussion, conclusions and recommendations in the review feel overly cautious and not fully grounded in how prostate cancer is managed today. The review places heavy emphasis on the risks of overdiagnosis and overtreatment, yet it does not adequately recognise how modern pathways such as active surveillance have transformed what early diagnosis actually means for patients.

Because my cancer was found early, I did not have to rush into radical treatment. I am on active surveillance, which means my cancer is being carefully monitored while I continue to live a normal life. This is exactly how low-risk prostate cancer should be managed. Without early detection, that option would not exist – I would instead have faced a later diagnosis with fewer choices and a much higher risk of needing aggressive treatment.

The review seems to assume that finding more cancers automatically leads to unnecessary harm, but this overlooks the fact that many men can now be safely monitored rather than treated. This fundamentally changes the balance of benefits and harms, yet it is not reflected clearly in the conclusions or recommendations.

The review also fails to fully acknowledge inequalities in access to diagnosis. Men with private healthcare are far more likely to get timely MRI scans and biopsies, while many NHS patients are still reliant on PSA alone. This creates a two-tier system where early detection – and therefore the chance to use active surveillance – depends on financial means rather than clinical need.

Overall, the recommendation not to introduce screening feels based on outdated thinking. It does not reflect modern diagnostic tools, modern management strategies like active surveillance, or the real consequences of late diagnosis. From a patient's point of view, a policy

that denies men the chance to find cancer early – and to avoid unnecessary treatment through careful monitoring – is not justified.

Recommendation comment:

Yes, prostate cancer screening should be recommended.

My own experience shows why. My PSA was low and I would never have been diagnosed if further tests had not been done. Yet I did have prostate cancer. Because it was found early, I am now on active surveillance, which means my cancer is being carefully monitored without the need for life-changing treatment. That is exactly how early prostate cancer should be managed – detected early, watched closely, and treated only if it becomes necessary.

Without screening, men are far more likely to be diagnosed later, when the cancer is more advanced and aggressive. At that point, active surveillance is no longer an option and men face surgery, radiotherapy or hormone treatment, all of which carry serious long-term side effects. Screening does not mean everyone has to be treated – it means everyone has the chance to be diagnosed early enough to make informed choices.

Screening should also be recommended because the current system is unfair. Men who can afford private healthcare are much more likely to get MRI scans and biopsies, while many NHS patients are reassured by a PSA test alone, even though PSA is not reliable. A national screening programme would reduce this inequality and give all men a fair chance of early diagnosis.

Modern tools such as MRI and risk-based assessment make it possible to screen more safely and accurately than in the past. The argument that screening causes too much harm is based on outdated approaches that no longer reflect how prostate cancer is diagnosed and managed today.

Screening gives men knowledge, choice and time. Without it, too many cancers will continue to be found too late, when lives, health and families have already been put at risk.

Alternatives comment:

There are many ways the NHS or government could support men with prostate cancer beyond a national screening programme. Speaking from my own experience, awareness is critical. Earlier in ***** I was visiting the loo constantly, yet I didn't realise it could be a sign of cancer. Many men ignore symptoms because they seem minor or embarrassing. Clear public campaigns, guidance from GPs, and information targeted at older men could make a huge difference in encouraging men to get checked sooner.

Access to timely diagnostic tests is also essential. My PSA was *****, and yet I had prostate cancer. I was fortunate to have private medical insurance and could get an MRI and biopsy quickly. Many men relying on the NHS may never get that opportunity, leaving cancers undetected until they are far more serious. Faster access to modern diagnostics for all men would reduce this inequality and allow more men to be diagnosed early, with better outcomes.

Support for high-risk groups is another vital step. Black men, men with a family history, and older men face higher risk, but current systems do not prioritise them. Targeted information, assessment, and monitoring would ensure these men are not left behind and could save many lives.

Finally, structured follow-up and active surveillance programmes are crucial. Because my cancer was caught early, I am on active surveillance – carefully monitored without needing radical treatment. But without clear guidance and regular monitoring, this option would not be possible. Providing men with ongoing support, reassurance, and psychological care can help them manage the uncertainty of diagnosis and maintain quality of life.

In short, the NHS and government could save lives by combining awareness, faster access to diagnostics, support for high-risk groups, and structured monitoring programmes. These measures, alongside or ahead of a formal screening programme, would give men the chance to detect cancer early, make informed choices, and avoid unnecessary treatment – something I know from experience can make all the difference.

Other comments:

Yes, I have several recommendations based on my own experience with prostate cancer.

First, the NHS should create clear pathways for men with persistent symptoms, even if their PSA appears normal. My PSA was *****, yet I had cancer. Without further investigation, I could have been left undiagnosed until it was far too late. Persistent symptoms must always be taken seriously.

Second, there needs to be better public awareness and education. Earlier in *****, I was visiting the loo constantly, but like many men, I did not recognise this as a warning sign. Prostate cancer must be talked about openly so men feel confident seeking help early.

Third, access to modern diagnostics such as MRI scans and targeted biopsies should be available to all men, not just those with private insurance like I had. This would reduce dangerous inequalities in early diagnosis.

Fourth, structured follow-up and active surveillance should be standard. Because my cancer was detected early, I am now on active surveillance – monitored carefully while avoiding unnecessary radical treatment. Clear guidance, regular check-ups, and psychological support make this safe and manageable.

Finally, high-risk groups must be prioritised. Black men, men with a family history, and older men face higher risk and need targeted assessment and monitoring to reduce disparities.

I would also note that public awareness and support for a national screening programme is strong. Well-known figures such as David Cameron, King Charles, and even current Prime Minister Rishi Sunak have all publicly emphasised the importance of tackling prostate cancer. Their support, alongside lived experiences like mine, highlights that a national programme would be widely welcomed and could save thousands of lives.

In short, the NHS should focus on early detection, equitable access, risk-based monitoring, and patient support. These measures, alongside or in preparation for a formal screening programme, would give men the knowledge and choice to manage prostate cancer safely, prevent unnecessary suffering, and save lives.

P647	Affected Comment: I was diagnosed with stage ***** prostate cancer in ***** Evidence Comment: No Discussion comment: No Recommendation comment: Unsure about screening, although I am sure that advice on symptoms needs an overall. Current advice is almost entirely based on ability to pass urine. Almost no reference to sexual aspects, which after all is the function of the prostate. In my case I had and have no difficulties passing urine. However about ***** years ago I noticed orgasm was less good, even slightly painful. More recently fluids associated with sexual activity reduced to almost nothing and erections began to reduce. I also began to notice slight discomfort in the perineum area. I have metastasized prostate cancer that has spread to upper femurs, pelvis, spine, ribs, shoulders and sternum, despite this I still have no difficulties passing urine. Alternatives comment: I think that a simple online tool could identify those who might benefit from a PSA test. It could consider all aspects in order to spot warning signs of illness – tiredness, perineal discomfort, urination, erections, orgasm and so on.
P648	Affected Comment: It has affected more than one of our friends. Evidence Comment: I feel this is a cost, not evidence, issue. Earlier screening could save costs, longer term. Discussion comment: Need action now, not discussions. Recommendation comment: 100%. The statistics, & frequency, are similar to those for breast cancer. So the screening should be as regular, & as pro-active. Alternatives comment: Still feel regular screening is the answer. Along with this, stronger awareness campaigns. Offer routine checks via pharmacies as currently happens with blood pressure. Other comments:

	6 monthly blood tests over the age of 50, say.
P649	Affected Comment: I was diagnosed with prostate cancer in *****. I was advised to have a robot assisted prostatectomy. This had horrible side effects, leaving me hopelessly incontinent. I had a Gleeson Score of *****. It turned out that the cancer had escaped the prostate. I have been on hormone therapy since then. My impression is that I can't be cured. Had there been a screening programme in place, I am sure that my cancer could have been caught and treated whilst still in the prostate. Evidence Comment: N/A Discussion comment: N/A Recommendation comment: Screening should be mandated. My life and much NHS resources could have been saved with earlier diagnosis. Alternatives comment: The support for men with prostate cancer is very varied. There are some voluntary organisations doing a great job, but there is nothing in some areas. Other comments: N/A

P650	Affected Comment: My husband passed away at ***** in *****. He had an aggressive Gleason ***** prostate cancer diagnosed in *****. History of hormone cancer in his family yet no BRC gene fault. Screening carried out privately through work in ***** and was referred to GP as PSA high. GP felt there was no cause for concern and no further action was taken or sought then or in the future. He requested a further PSA ***** after experiencing erection problems. PSA was *****. Spread to lymph nodes. Incurable at that point. Evidence Comment: Absolutely could have been treated earlier. Who knows he may still be alive and well. Discussion comment: I strongly believe that screening programs supported by the NHS would have made all the difference. There would have been more understanding of the PSA numbers and how high is high may trigger warnings with more knowledge. My husband was ***** in *****. His PSA at ***** would have been concerning yet at ***** was just within the acceptable range. I knowing what I know now would have encouraged him to seek a further PSA test ***** months later and see if the baseline had changed. I have spoken with senior Prostate and cancer professionals and they are resoundingly supportive of screening and the benefits. I don't believe the claims of false positives should be a deciding factor for not providing screening. Better to know than not. His ***** children are very aware that they are at risk of any hormone cancer and will seek screening and whatever they can in the future. Recommendation comment: Definitely yes. I have covered off my reasoning in my previous answer. I will add that my husband had no usual symptoms at any point. It took an embarrassing erection problem to go to the GP. It took him ***** months to pluck up the courage to ask. A further delay. Alternatives comment: There is no denying that Prostate cancer kills. The numbers will speak for themselves once a proper screening program is introduced. At early stages it is curable. To limit the screening to just guys with the faulty gene is going to miss thousands. Furthermore, gene testing is often only sought after diagnosis so in many cases the proposed program is going to miss its target market. Such a simple test, effective treatments available if caught early vs invasive chemo, tablets and injections which dramatically affect a person for the rest of their life when caught late. The government have a super power to change this. I would hate for others to go through what we have. I know they are though. Very sad for the unnecessary pain and suffering. The costs of treatment and support later down the line vs a PSA test !!? It seems a simple decision for me. Other comments:

	***** years on it's still as fresh in my memory. We are rebuilding our lives but it maybe could have been very different. Losing your Dad at *****during Covid with no support network due to restrictions will live with him for the rest of his life. First ***** born *****. will never know him. Getting married *****. An important person missing. I think it's important to understand there are actual people not numbers. And the knock on effect of one policy decision affects the future of others.
P651	Affected Comment: This condition has affected three close friends and had a substantial mental and financial impact on their families and colleagues. Thankfully they all survived but if they had not, the consequences would have been frightening and an additional cost to the country. Recommendation comment: It doesn't matter who you are as it can affect all males. It is a no brainer that men should be screened. Alternatives comment: The Government should be aware of the public's feeling on this matter. If they are not, they should not be in a position of authority. To help they need to make a positive decision without further delay. Saying yes is the only sensible decision. Other comments: Get on with it.

P652	Affected Comment: Multiple friends have been diagnosed with prostate cancer. They have undergone a number of different treatments for the condition, including surgery. All of them, to a man, say “Get yourself checked regularly” and “Early diagnosis is key to survival”. Evidence Comment: There are so many instances where men in the public eye have been diagnosed with stage 4 prostate cancer only to be told by the medical profession words to the effect of, I’m sorry, there’s nothing we can do, if only you had got yourself diagnosed sooner. Recommendation comment: Yes, of course it should. Why? In a nutshell, early diagnosis can save lives. Here’s the experience I went through a few years ago at my (then) local surgery: Having recently moved and registered with the local surgery I attended a wellness check. I asked the nurse if she would check my prostate. She asked why. I told her that as a man of a certain age prostate cancer sufferers had told me that I should get checked. She said I’d have to book an appointment to see a doctor and convince them that I should get checked. The doctor tried to dissuade me for all the usual reasons. No correlation between positive and negative test results and actually having the condition, intervention doing more harm than good etc. I said “If a test revealed a high PSA result what would you do?”. In the absence of an answer I said “I suspect you’d recommend another test in a few months time, and if that was high too you’d recommend further investigation”. The doctor nodded. I replied “There may not be a direct correlation between test results and actually having the condition, but there is certainly an indirect correlation or you wouldn’t recommend this. In addition, my friends who have had surgery for their cancers tell me that they have repeat PSA tests to confirm that the surgery was successful.” Men should not have to go through this farce. 1 in 8 of us will get prostate cancer. Some of those less able to argue their case than I will get the disease and will die from it due to late diagnosis. It’s all very well for the UK NSC to shrug their shoulders, but what would they say to the families of those who have and will die as a result of their decision?

P653	Affected Comment: I was diagnosed with high risk prostate cancer in ***** (at the age of *****) and I received my treatment throughout ***** Evidence Comment: I understand that there are concerns regarding how reliable the economic model used is Discussion comment: I consider that REGULAR SCREENING should be carried out for ALL MEN (over a certain age) IRRESPECTIVE OF THEIR RISK CATEGORY Recommendation comment: Screening should DEFINITELY BE RECOMMENDED. Screening is important to me as, at the end of ***** (at the age of *****), I was diagnosed with high risk prostate cancer and MY DIAGNOSIS WAS QUITE BY CHANCE. Following my hearing a medical discussion on the radio I contacted my GP to request a PSA test as I had not had one for ***** years. I had to ARGUE with the practice nurse to get a test AS I HAD NO SYMPTOMS and I WAS CONSIDERED AT LOW RISK. That test came back showing elevated levels of PSA which led to further investigations (MRI and CT scans and then biopsies) which led to my diagnosis of HIGH RISK PROSTATE CANCER. Thankfully my cancer was contained within the prostate. I was fortunate (if a cancer diagnosis can be classed as fortunate) that my CANCER WAS DETECTED EARLY. I received radiotherapy in ***** and hormone therapy throughout *****. I hope to see the consultant oncologist for the last time in *****. However, whilst my cancer WAS DETECTED EARLY and HAD NOT SPREAD, there is NO GUARANTEE that the treatment has been successful or that the cancer will not return. Therefore, I consider that REGULAR SCREENING should be carried out for ALL MEN (above a certain age) IRRESPECTIVE OF THEIR RISK CATEGORY Alternatives comment: There should be a screening programme as many men (like myself) have no symptoms and are considered low risk. Other comments: In addition to annual PSA tests men should also have an annual MRI scan which has been proven to be significantly more reliable at detecting prostate cancer in men with normal PSA levels and no symptoms. An early diagnosis is essential before the cancer spreads outside of the prostate.

Affected Comment:

Yes indeed it has. As a result of a totally random free screening that was advertised, myself and two friends set off to go to a location to get tested. Unfortunately the site was double booked ending in multiple cars being unable to get there.

By pure luck my friend was the one that was successful, he tested positive for prostate cancer. He is still in remission after treatment. The two other of us have since been tested at our doctors, however I was basically interviewed by my doctor as to why I thought I needed a test before I could finally get one.

Evidence Comment:

After looking at the review I am frankly appalled that males should be considered lesser citizens than females. I applaud all the test offered to my wife and other females, as important life saving early medical prevention. What makes me and other males expendable. Do not men deserve the right to screening for what is rapidly becoming a huge killer amongst us. It would appear to me this is blatant discrimination. That a man should have to go begging to his doctor for a medical test to possibly save his life in this day and age is degrading, ridiculous and totally unacceptable.

Discussion comment:

In an age where the importance of men's health is slowly overcoming the stigma of older generations. All be it a very slow realisation and process. It is frankly appalling that this review seems to have been scaled back in its concerns.

Recommendation comment:

Of course screening should be recommended.

Firstly men are as entitled to the same screening care as women have now got. This screening should not be based on ethnicity or statistical risk factors, we are all at risk.

The health service can cope and must cope. How over diagnosis, or over cautiousness, can possibly be a reason to limit screening is beyond me.

This early detectable condition could and should be screened without being left, before it's too late. Too many friends have died.

Alternatives comment:

An organised screening programme is the only way we will prevent the untreated deaths occurring. Doctors should be proactive not reactive.

Other comments:

It feels to me that it is imperative that the early diagnosis and treatment of this debilitating disease is undertaken.

I fail to see how a 2,3, or more year reviews of this decision will improve the health outcomes of those affected by this horrible disease. It takes the life of far too many men, husbands, dads and

	granddads as it is, whilst being treatable. This is an absolute travesty and something we as a society should be ashamed of. Care should always be taken when deciding on health care decisions and I understand the balance required when making these decisions. But I would really like any decision made to better consider the results of a man future life, with all the others this extra chance affects, above the purely medical, financial and clinical results driven influences. Please give us men a chance. We may not be the best at looking after ourselves but we do deserve this.
P655	Affected Comment: Diagnosed with Gleason ***** prostate cancer *****. Good friend has stage ***** gone into lymph nodes. Evidence Comment: I didn't suspect that I had any issues with my prostate but was recommended to get psa test to rule it out by works occupational health. The GP only agreed to the test because of the occupational health recommendation otherwise I would have potentially been refused. I am lucky because I have early stage and can monitor the situation and make informed choices on treatment paths. If refused the test it could have spread out of the prostate. Discussion comment: Unnecessary harm is being used as an excuse for cost reasons above the 12000 men that will die. Many younger men still working have medical insurance through their work which could ease the burden on the NHS Recommendation comment: I think screening should be offered to anyone who offered it accepts. It should also be offered to anyone asking for it as well.

	Alternatives comment: Better regional centres of excellence that offer alternative treatments like focul therapy. ***** is as ***** as it has currently reached and that is via private healthcare.
P656	Affected Comment: Husband has an enlarged prostrate and has had bladder cancer.My brother undergoing further scans re high PSA rates Recommendation comment: Yes as early detection is vital.
P657	Affected Comment: TEST for email acceptance – please ignore
P658	Affected Comment: I was diagnosed in ***** at the age of ***** after self referring in ***** to my GP who referred me quickly to Urology. I was seen fairly quickly (*****) by urology had a DRE and micturition flow test. An MRI ***** with contrast. with a diagnosis on the *****. Biopsy ***** results of this received ***** my Gleason scale was *****. With lymph node implicated Bone scan ***** First hormone implant ***** I had ***** fractions of radio therapy staring the ***** hormone implant every ***** months. Evidence Comment: I think voluntary (self ref) screening at 40 especially if father / sibling has hx of prostate cancer. Mandatory invite for screening at 50 with 12 monthly PSA testing thereafter. Recommendation comment: Absolutely recommend screening. Timely detection and treatment better outcomes. Alternatives comment:

	PSMA CT /PET Multiparametric certainly looks like a useful opportunity. If I understand correctly this is primarily in respect of reoccurrence cases. I hope that it might help in first line detection also. Other comments: Not at this time
P659	Affected Comment: I have early stage prostate cancer, it was caught on by sheer fluke, it all started with swollen legs, my doctor thought it was my heart, but after several test, CT scans, and M R I scans, then a biopsy was performed, that's when it showed up, I was given hormone injections, then ***** sessions of radiotherapy, I also suffered depression after the injections, still on 100gms of Sertraline, have to ask for PSA blood tests to check if it has gone down or up, so yes absolutely a National screening test is vital, I was lucky mine was caught on early enough. Recommendation comment: Absolutely 100%, it should be done, ASAP,, to save more lives, urgent funding given ASAP, and no holdups whatsoever!!! Alternatives comment: The only other test I am aware of is the P S A blood test, and a specialist laboratory to be established, in each and every section of the U.K., not just England and Wales !!
P660	Affected Comment: My father had a prostate op in his 70s, and I was actively monitored for several years before increasing PSA results indicated that I should have treatment, which is now completed. I have warned first degree relatives that they should be tested Evidence Comment: It's incredible to me that the committee rejected national screening of all men over 50, when there are 12000 deaths per year from prostate cancer, most of which can be saved by early diagnosis and treatment Discussion comment: See above, I'm alarmed at this negative conclusion and recommendation when so many people die annually of prostate cancer, which is eminently treatable if detected early. Why should a general screening programme be denied when it has long been in place for many other cancers? Recommendation comment:

	See above, yes, I strongly feel that widespread screening should be implemented as soon as possible Alternatives comment: In my view, there is no satisfactory substitute for a general screening programme for men over 50 years old Other comments: Please act on this as soon as possible, lives are being needlessly lost
P661	Affected Comment: It has. My husband was diagnosed very late with a Gleason score of *****. It subsequently “ate” his spine and he died. ***** of his ***** sons were diagnosed with a score of *****. One had his prostate removed and ***** years later died with necrotising pancreatitis at *****. The other had radiotherapy. Discussion comment: I am just disgusted that automatic testing of this dreadful disease is not available at the age of 50, or even earlier. Those who make this decision obviously have not listened to those who have the knowledge and capacity to ensure the wellbeing of men. Recommendation comment: Yes. Women have automatic testing on a number of things. I would add that the testing for pancreatic cancer should NOT stop at 70 or so as other tests do. My husband was ***** , and illness is not always age limited. Alternatives comment: Would like to know what the alternatives are so I could make an informed decision. Other comments: If men request the PSA test, at any age, it should be provided and not put on hold until later, when it is often too late.
P662	Affected Comment: I was diagnosed with aggressive prostate cancer in ***** following a private urological consultation for an unrelated issue, which turned out to be nothing. Luckily the consultant asked whether I had ever had a prostate test. I had not and agreed to a finger and blood test which showed a PSA level of *****. Following a scan and biopsy I had my prostate removed and subsequently had radiotherapy when my PSA started rising again. I was aged ***** when I was diagnosed and had no symptoms. It is therefore highly likely that without the good luck of having to see a urologist who encouraged me to get tested my prostate cancer would not have been identified for some considerable time and would have progressed to a stage where treatment options would have been reduced and I would quite likely not be alive today. Although I now

	again have a rising PSA level indicating metastatic disease I am alive over ***** years after the diagnosis and in that time have been able to see my children marry and seen the birth and early years of ***** grandchildren as well as spending precious time with my wife and family. I would almost certainly have missed all of that without the prostate cancer tests. The modest inconvenience of having the tests is nothing compared to the last ***** , and hopefully many more years and I absolutely believe that every man should have a similar opportunity as I had, but not via a test arising from luck, but from a properly structured universal screening program. This should not be a lottery left to chance. Recommendation comment: Absolutely should be recommend for the reasons set out above.
P663	Affected Comment: My friend was diagnosed in *****. He involved ***** Club in PSA testing and we have tested ***** men over ***** years. Last year we had a ***** red result in ***** men. That is a *****% increase on the previous year. Evidence Comment: I have no comment. Discussion comment: It is a mistake to not test men over 40, choose what ethnicity they are. Recommendation comment: Our experience at ***** strongly indicates that screening should be done. Alternatives comment: Early detection is key and a sceening programme will provide that. This is not about helping people when the condition has been diagnosed but about detecting it before it gets a hold. Other comments: No.

P664	Affected Comment: My husband was given a prostate cancer diagnosis (Gleeson Scale *****) in *****. He has one from being fit and active (*****) to being unable to walk any distance and requiring 24 hour care. The original mis-diagnosis was BPH and the medication to treat the condition masked the cancer. The BPH diagnosis was as a result of an A&E admission thought to be a UTI. At this point had a PSA blood test been done the cancer would have been found a lot sooner. After being discharged, my husband was fitted with a catheter with a ***** month review. It was difficult to get a doctor's appointment to review the situation and it took ***** months to get a PSA blood test. Presenting with symptoms in ***** and the cancer diagnosis in *****. We then had to wait until ***** to get a TURP procedure and radiotherapy did not start until*****. So, ***** months. The decline in his health has affected everyone. ***** is depressed about his condition – the urinary incontinence experienced pre- treatment still persists. There is no dignity with this condition. The stress from this has caused other issues (TIA) which now severely affect his cognitive and mobility functions. Family and friends no longer wish to visit because they cannot bear to see such decline. This makes us feel isolated and un-loved. It is costing a fortune in incontinence wear and running the central heating and washing machine every day. ***** receives attendance allowance and I receive carer's allowance at the higher rate because he needs 24 hour care. If the diagnosis had been sooner, I am confident the my husband would be in better health and there would be a saving to the Government through reduced costs of benefits and prescriptions etc. There was very little in the way of advice and support – we were given a few web-site addresses and that was it. Evidence Comment: I was unable to find the evidence base that was used. I imagine that it is only available to professionals. What I would say, is that I have a "lived experience" of a late diagnosis. There was a real difficulty in getting the "magic" PSA blood test. It seemed that each decision was based on financial issues rather than the wellbeing of the patient. Given my husband's age he should have been more eligible for the PSA blood test and the subsequent tests to confirm a prostate cancer diagnosis. Discussion comment:

Some of the conclusions are flawed. The report states that there are life long side-effects of the cancer treatment namely:

urinary incontinence

erectile dysfunction.

These two symptoms were evident prior to the cancer treatment and continue post treatment.

I am disappointed to find that only men with the BRCA1 or BRCA2 gene can be eligible for the screening programme. Does that mean that all men over the age of 45 can have a genome test to find out whether they have this problem. How much would that cost compared to the PSA blood test?

I think the report is overly cautious because of the numbers who are diagnosed, particularly those with slow growing prostate cancer. Those with slow growing cancers could be effectively supported through monitoring and education. Perhaps even have a different term for such cancers.

My experience leads me to believe that the decision not to test all men is based purely upon numbers and the cost to the NHS. In addition, "the economic model used for disease effectiveness & cost" leads to a postcode lottery in getting the care and resources that are required especially where population demographics are applied.

Recommendation comment:

I think that screening should be available to all men over the age of 45.

As a woman I am eligible for Breast and Cervical cancer screening, so why can't men have the PSA blood test. I know that the PSA test is 100% accurate, but it is the best tool in the box that we have so far. From our experience, the cancer was aggressive and if it had been detected earlier, my husband would be in a much better state of health than he is now.

Alternatives comment:

There needs to be a better system of education and local support, especially if going forward we are to continue with ad-hoc testing.

Whilst the radiotherapy has been successful, the monitoring of the cancer seems to have stopped. I have rung the hospital several times to request the paperwork for a further PSA blood test (now 6 months overdue).

This is evidence that everything is done on a "cost" basis.

Other comments:

I know that screening is complex and investigations are costly but it seems that Prostate Cancer is taking so many lives not just in terms of mortality but also in terms of health and wellbeing.

It seems really unfair to say that only those with a BRCA1&2 are eligible for a screening programme – how do you know if you have this?

Lived experience is just as important as clinical evidence. The damage caused by a late diagnosis is devastating, not just for the patient but also for the family and friends. A late diagnosis probably costs more in the long run.

	The support systems are not in place and/or cannot cope with the current volume and to deny testing to those who are at a higher risk seems based purely on a financial basis. I think the policy should be kept under constant review rather than a re-review at some point in the future. In addition, patients and their communities should be included in any future decisions. There needs to be easier access to the PSA blood test, better GP support and perhaps community drop in sessions where people can raise concerns or educational sessions.
P665	Affected Comment: Both neighbours have been diagnosed with prostate cancer. One sadly died last year due to the late diagnosis. Before he died he urged me to get a blood test to include PSE. Now I am taking tablets for enlarged prostate. Prior to his advice I was unaware of the risk. As a major killer amongst older men I fail to see why the Government do not see this as a priority. The financial cost of treatment alone surely warrant another look at this issue. Recommendation comment: It must be recommended. I have paid National Insurance for the past 70 years and it seems my reward is a game of roulette with my last years. Bet my pension that MP,s don't have this worry. Alternatives comment: Better education,publicity to diagnose early. PSE tests on demand,pharmacy as providers,.

P666	Affected Comment: My GP in ***** was willing to authorise a PSA test around ***** years ago when I was in my late *****. This provided a benchmark although upon moving to my present home, my ***** GP wasn't keen to authorise a subsequent test when I requested that ***** years ago at the age of *****. After considerable persuasion, he did authorise a test which showed my level had increased but was still within "an acceptable" range. Despite no glaring symptoms, I asked for a further test in ***** which again I had to argue for. This time, the rate at which my PSA level had elevated prompted a CT scan from which a prostate abnormality was detected. This was confirmed by biopsies (probably the most painful part of the whole process) and I was notified that I had a Gleason score of *****. Late in ***** , I had my prostate gland destroyed by SABRE radiation at the ***** in *****. Whilst somewhat uncomfortable, the treatment was on an out-patient basis lasting just over a week and was totally successful. Without that intervention, I suspect that I would have developed Stage ***** cancer some time ago. I now have an annual PSA test with the sample taken during the run-up to my normal review. I am just an average white male and I know of several friends and acquaintances (mainly white males) who have suffered from Prostate Cancer, some of whom have died prematurely from the disease and others have had to be treated for more advanced forms. The inconvenience of a poor or non-existent sex-life is nothing to an early and potentially painful death. Recommendation comment: I strongly believe that screening should be part of the NHS's Annual Health Check for ALL men over 40. As we are expected to provide an annual blood sample for various other conditions, a small additional amount drawn at the same time will take no more time and a cause only a minuscule amount of extra work in terms of analysis. I cannot agree that "only those who have the BRCA gene variant" should benefit from the test because a) there are risks that many males will potentially have early stages of Prostate Cancer which will progress to more serious levels and b) those with the BRCA gene variant may not know they have that anyway so may not seek screening. There is a significant benefit in having a record of one's PSA level so that change can be easily detected and rapidly acted upon. Medical practitioners and patients alike know that early detection is always more likely to bring a positive outcome and save the subsequent costs to the NHS in treating latter stage prostate cancers. The NHS believes in general cervical cancer screening for women so why shouldn't men be offered screening for perhaps the largest killer disease that they face? The NHS also offers Bowel Cancer Screening for a certain age range without exception because it is effective and yet to deny Prostate screening to most because it may reveal a small number of false positives seems counter-intuitive. Alternatives comment: Education is key. Perhaps an annual publicity programme involving all media options for just one week a year could be arranged and I would suggest that happens in mid spring because that

	would be beyond the winter illness period and prior to summer holidays – that is assuming the National Screening Committee reverses its present position of course.
P667	Affected Comment: i have an enlarged prostate which was found when i told doctors i was going to the toilet too often, particularly during the night. After a close friend was found to have prostate cancer i asked for a test to be done and the answer i had "has't it already been done". Each of the last ***** when i have routine tests for a wide range of problems i have needed to ask for this test and justify it. I complained so much last year they agree d to test me every year they do the other blood tests. Evidence Comment: too many people are affected by prostate cancer which is a life threatening disease. This must cost the NHS to treat and cure a lot more than screening. Discussion comment: not wide reaching enough. A people potentially at risk should be screened. Make and run more scanners. Recommendation comment: cheaper in the long term Alternatives comment: other alternatives are not very effective Other comments: no

P668	Affected Comment: I was diagnosed with prostate cancer aged *****, the disease was well established at this point. The diagnosis was due to a GP ticking the box at a routine blood test. Since then I have had radiotherapy, and ***** years later I had my prostate removed as the cancer had returned. This last operation has left me permanently incontinent and with erectile dysfunction. In ***** the cancer metastasized to my pelvis and I had further SABR radiotherapy. The last ***** years have not been easy for my family, or myself, and I think the hardest part has been the waiting for treatment and results. I do believe that if I had been screened routinely at fifty years old then the disease would have been easier to cure. I know other countries do this as a matter of course. Evidence Comment: I am speaking from a personal point of view. I believe that the diagnosis of prostate cancer on your family members and family life is vastly underplayed. The whole issue leaves a feeling that you should be grateful for the treatment that you eventually receive, and that you should just get on with it. I am grateful to the individual members of staff of the NHS that treated me, but I am not grateful to the UK government who have dragged their heels for years over the treatment of this cancer. It makes one feel that successive governments care more about the cost involved than whether the treatment should be available to all men in the UK. Discussion comment: Yes, I think that the economic model used by the NSC is flawed and does not reflect the actual problems encountered by families in regards to the immensity of this issue, therefore I feel that the recommendations and conclusions of this review is not for for purpose! Recommendation comment: As I have stated above I feel that there is too much emphasis on the monetary side of this review than the treatment side. The question of overdiagnosis and overtreatment are over played. I once asked about why this country does not routinely screen for prostate cancer and the answer was that it is not always reliable and that various causes can affect your PSA test and that this can bring on needless anxiety. I do not support this notion and believe that it is better to follow up on PSA results whether it is a false reading or not. I certainly would have wanted my diagnosis to have been earlier and treated sooner, and I believe all men in the UK should have a right to that treatment. Alternatives comment: The current ad hoc system is unfair and whether high risk or not too many men fall through the net. A PSA test is one blood test and would not break the bank by enabling all men to access this routinely. More emphasis should be put on education. I have spoke to many friends who have no awareness of what prostate cancer does or is. Other comments: Policy for screening for prostate cancer should be under regular review. Too much emphasis is placed on technical detail rather than the human impact. Lived experience should be considered, along with clinical evidence. For example the impact on family life, including work, financial, social, sexual, and many other issues that become distorted and difficult to manage after a prostate cancer diagnosis!

P669	Affected Comment: I was diagnosed with Prostate cancer in *****. I visited my GP when ***** told me he had prostate cancer and had had his prostate removed. I was able to go on Watchful Waiting until my consultant informed me the cancer had grown considerably and the prostate should be removed in *****. In ***** my PSA level began to increase again and I was offered radiotherapy in ***** to kill off any possible prostate cancer cells remaining. This treatment was worse than the operation but proved successful with my PSA remaining negligible since. I was diagnosed with bladder cancer in ***** and had the tumour removed. I also seems to have been successful. This whole episode of my life has been extremely traumatic to me and my family with constant worry about the next test results. I believe my radiotherapy caused my bladder cancer. The earlier men are checked the better. Recommendation comment: Screening is absolutely necessary. The earlier men are checked the better. The trauma of late diagnosis is shattering for the person and their family. There seems to be a lottery in place at present whether you have a GP who is willing to have prostate cancer checked immediately and others who dismiss the possibility of prostate cancer. My ***** died because his GP was not as proactive as mine. His prostate cancer was untreatable by the time it was actually diagnosed long after he first approached this GP. I have survived ***** years so far past my diagnosis. My ***** has to live with the consequence of the intransigence of the GP. Please stop others suffering this way.
P670	Affected Comment: Yes. I am ***** years down the line from Radiotherapy. I am in my ***** and had to ask for a test which measured *****. I have great regard for the care and treatment I received. The aftercare has been patchy. Evidence Comment: My main concern is that both my brother and I have suffered. Whilst I believe that a screening programme is essential, I do not understand at all why screening should exclude siblings or children of confirmed cases. It should include all higher risk groups including black men. Discussion comment: See above. Also, as a retired *****, the conclusions do not seem properly evidence based. I.e. where and how frequently is the risk actually found and how do we extrapolate that to a proper diagnostic tool. Recommendation comment: Yes. I believe that the circumstances of risk are not fully established. That is that we cannot say whether any individual is not going to be affected nor at what point you reach statistical insignificance. Alternatives comment: I do not know of alternatives to PSA tests at the moment.

	Other comments: Genetic exposure is obvious. Why not establish a data base of children of patients affected. It could be voluntary and contributed to by medical professionals
P671	Affected Comment: I was diagnosed with Stage ***** (Gleason *****) metastatic prostate cancer in ***** purely by accident after a health check revealed sugar in my urine and so a blood test for HbA1c was recommended to confirm Type 2 Diabetes. I requested a PSA blood test at the same time and after an inconclusive digital rectal examination by my GP, he reluctantly agreed to give me a PSA test. This PSA test revealed a PSA level of greater than ***** which immediately diagnosed metastatic and incurable disease despite me being asymptomatic. My story of a late stage incurable diagnosis is not unique, more than 15,000 in UK per annum are diagnosed at Stage 4 with less than 50% 5 year survival. As there is 100% survival from curable Stage 1 – 3 PCa then then the benefits of screening all men over 50 are obvious. Evidence Comment: Firstly, the evidence that the NSC appears to have missed is the benefit to men offered by earlier diagnosis through a pathway that begins with PSA test and not a DRE, is then followed up through multi-parametric MRI and then escalated to guided prostate biopsies. The harm due to potential mis-diagnosis is far outweighed by the benefit of early diagnosis. Over-treatment through androgen deprivation is considerably less onerous than docetaxel chemotherapy, the latter intervention only after confirmed diagnosis. Secondly, the draft decision to treat genetically at-risk men carrying BRCA1 or BRCA2 mutations misses the key point that many men do not know if they carry these variants. In addition, my own polygenic risk score of ***** indicates that other genes contribute to genetic risk. Thirdly, key risk groups such as Afro-Caribbean and those with a hereditary risk (father or grandfather with PCa) have been ignored and targeted screening of such risk groups carries even greater benefit over potential harm. Finally, the health economic arguments make little sense when a simple PSA test costs £5 whereas more advanced interventions, including late stage palliative care can cost £10K to £500K per patient. Discussion comment:

	The NSC needs to properly consider the real risk of harm vs the real benefit of earlier diagnosis, forgo fatuous economic modelling and at very least recommend targeted screening for ethnic and hereditary risk from at least age 50. Recommendation comment: Screening for all men based on annual PSA testing should be recommended. Those with Stage 4 incurable disease have less than 50% 5 year survival. As there is 100% survival from curable Stage 1 – 3 PCa then then the benefits of screening and early diagnosis for all men over 50 are obvious. Alternatives comment: I cannot think of a more sensible alternative to PSA-based targeted screening for those with ethnic or hereditary in the first instance leading to broader annual screening for all men over 50. Other comments: PSA-based targeted screening for those with ethnic or hereditary in the first instance leading to broader annual screening for all men over 50.
P672	Affected Comment: Myself, ***** and ***** friends have all had prostate cancer. ***** of them were diagnosed too late and although still alive will die from this cancer. There is only myself who was monitored for many years due to an enlarged prostate. The***** others had no systems and struggled to get a PSA test. The treatment the ***** friends who were diagnosed late have had to endure has been very distressing over long periods of time. Evidence Comment: I feel that the evidence doesn't seem to reflect real life. My above comments show that the harms of late diagnosis are underplayed. The cancer had spread to the ***** of one of my ***** , the ***** of another and the ***** of two other friends. The radiotherapy, chemotherapy and hormone treatment has been very difficult for them and their partners. Discussion comment: The conclusions seem overly cautious and uncertainty is being used as a reason for inaction. Why do we screen women for breast cancer and not men for a cancer that kills 12,000 men a year. The misery of late diagnosis is mentioned above. It makes me wonder if money has a place in this conclusion. I had a prostatectomy and although the long lasting consequences are unpleasant they are nothing like the suffering of my ***** friends who had a late diagnosis. Recommendation comment: Screening should be recommended. Targeted or risk based screening is a sensible first step. I don't understand the concerns about overdiagnosis or overtreatment. My cancer was indicated by an elevated PSA reading and confirmed by an MRI and biopsy. How can there be overdiagnosis when the Gleason score is taken into account. All treatment options and statistics were made clear to me and the form of treatment was my decision. My ***** who has an

	enlarged prostate and a PSA in the forties knows it isn't cancerous because of an MRI and biopsy. Alternatives comment: There should be clearer access to PSA testing. Me and my friends have all met with strong resistance from our GPs when it comes to PSA tests. I had great difficulty in obtaining 6 monthly PSA tests from my GP even after having my prostate removed. The return of prostate cancer seems very common amongst men who have had their prostates removed. Maybe GPs need better education and support but I would have thought that CPD would be mandatory for a GP as it is in many professions. GP staff seem completely ignorant about prostate cancer. It is well known that prostate cancer is more prevalent if a father or brother has had the disease but GPs seem oblivious to this fact. Other comments: The policy needs to be kept under constant review as new evidence emerges. Patients and other men need to be heavily involved in these decisions. I am writing as a patient with real life experience of this horrible disease and have no technical knowledge of prostate cancer. However I am aware that Prostate Cancer UK as well as actively working towards earlier diagnosis and better treatment for prostate cancer also support screening.
P673	Affected Comment: Yes – I was diagnosed with prostate cancer ***** ago had brachytherapy, radio therapy and the cancer was eradicated-I was then ***** and had no symptoms. PSA started at ***** and is now *****. My ***** has just been diagnosed and also had no apparent symptoms. Three of my friends – younger than me have also been diagnosed with prostate cancer -varying symptoms Evidence Comment: It seems the committee based their decision on evidence that they had gathered -it was not based on an independent large scale trial -it is disingenuous to make such a huge decision affecting so many lives on limited evidence gathered by the group who made the decision!! Discussion comment: The PSA test gives an indication of prostate cancer – there is then a series of interventions which include rectal examination, biopsy, body scans and the Gleason scale – if any man has got to that stage and has aggressive cancer cells I cannot see how they could be given unnecessary treatment!! If you have aggressive cancer cells they must need treatment-you can live with benign cells but after all those tests based on the original PSA and treatment options are provided how can they possibly be unnecessary? Recommendation comment: Screening must be recommended and introduced- for all men over the age of 60 years -it is a killer if not detected early and all my ***** other men had PSA tests on my persuasion to get tested based on my experience-because of that they had early detection and offered treatment – ***** successfully and hopefully my ***** will also be successful. Also had a number of friends

	who have been PSA tested on my recommendation and had low PSA results and not had to have any intervention but have peace of mind!! There was no unnecessary intervention!! Alternatives comment: The two I am aware of that are not radical or expensive are these two as well as the PSA test Saliva Test (Genetic/Polygenic Risk Score EpiSwitch® (PSE) Test It would be extremely positive if all three of these were available to screen men -those in high risk groups as well as anyone over 60 years old Other comments: The Government should continue with large scale trial covering men including Afro-Caribbean men to get a much wider evidence base than the committee based their decision on. In the meantime all men over 60 and those who gave a family history of prostate cancer should be offered screening -it is so important to have early screening to diagnose prostate cancer as early as possible to save lives -I was immensely grateful to a GP friend who advised me to have the test and undoubtedly saved me from the cancer Metastasizing into the rest of my body
P674	Affected Comment: My late father had prostate cancer and I too have been diagnosed with it. To date, I am on "active surveillance". Had it not been for a very minor routine consultation with my GP, for an unrelated issue, I might not have been screened in any way. While seeing my GP on that occasion several years ago, I mentioned the nocturnal visits to the toilet and the GP offered some medication. I was to try it for a while then report back to him. It had side effects which I did not like so I did ask for another appointment. This time the GP referred me to urology for a DRE. Thereafter, I was monitored by PSA tests annually. After several years, the PSA numbers rose to the point where further examination was required. The MRI showed matters of concern, and a biopsy confirmed the diagnosis of prostate cancer. it is of great importance to me that my own son has the facility to be tested and that he should not have to wait till he has problems. It is far too important for men to be in the position of not having a screening programme. I urge everyone involved in the decision making process to ensure that a screening programme is available nationwide, Evidence Comment: I am not medically trained but given the statistics, I cannot see a reason why more men cannot be involved in a screening programme. Discussion comment: I have answered this in the first paragraph of my submission.

	Recommendation comment: I have also written my response to this in the first paragraph. Alternatives comment: It depends how much GP practices can do and can afford. Other comments: Spread the word for men to be vigilant about their own health and talk to their GPs. Men should not be left to develop a disease that can be detected early and easily monitored and treated. Prevention is better than cure.
P675	Affected Comment: In ***** I requested a PSA test from my GP and was subsequently diagnosed with locally advanced prostate cancer in ***** following MRI, biopsy, CT, Bone and PET scans. At the time it was thought to be curable and I underwent a RALP procedure in *****. There was then a delay in my post operative follow up and I didn't have a repeat PSA test until ***** after my operation. This showed that my PSA was still raised and following another PET scan I was diagnosed with stage 4 metastatic prostate cancer as it had spread to the bones of my pelvis. Since then I have had chemotherapy and I am currently having radiotherapy, however my prostate cancer is now seen as incurable leaving me and my family with a very uncertain future. Evidence Comment: Having read the report it seems that the NSC were not looking at the current testing process when looking at how any screening programme would be run. They appeared to assume that a PSA test would automatically be followed by a biopsy with the associated infection risk, however my understanding is that the PSA test is currently followed by a non-invasive MRI scan and only if this shows any areas of concern is a biopsy done. Also there didn't appear to be any input from people actually affected by Prostate Cancer when identifying the benefit vs harm of treatment. For example, people in my position were considered as "break even" following my operation because I've been left with erectile dysfunction. If anyone asked me I would say that is a minor disadvantage the put against the alternative of being dead. Part of the report also looked at the cost of screening and subsequent treatment but didn't seem to take into account the cost of treating people when they are finally diagnosed. for example, just one of the drugs I am on costs approximately £4k per month. Discussion comment: there was a lot of discussion around the fact that men were receiving unnecessary treatment and this would increase if a screening programme is implemented. Surely this is not a problem

with the screening but with the treatment protocols. Unnecessary treatments shouldn't be offered.

Also people who have had those unnecessary treatments have not been consulted to see how they feel about the resulting side effects. They will have had these explained to them before choosing to go ahead with treatment and therefore may not see the side effects as an issue. Hence the outcome of the NSC may be incorrectly skewed towards harm.

Recommendation comment:

I believe screening should be recommended for all men over 45.

I understand the current guidance to GPs is to not promote the PSA test and to only give it to men who are exhibiting symptoms. Fortunately my GP was happy to give me a PSA test without symptoms and my cancer was found. It was up to me to go and do battle with the GP to get a test. Had I been invited for screening then my cancer would have been picked up earlier while it was still contained within my prostate and I would probably now be clear rather than facing an uncertain future.

If screening helps other men get diagnosed early and saves the lives of even a small number of men then it's worth doing. The PSA test could then be replaced when a better test is developed.

Alternatives comment:

I believe the first step in the process is diagnosis so some form of screening is crucial. Following diagnosis then better staging and associated treatment pathways need to be developed to reduce the incidence of overtreatment, thus reducing the perceived harm caused by treatment.

Other comments:

Change the guidance to GPs so that they actively offer the PSA test to men over 45 – 50. That's not to say they should specifically invite men in just for the PSA test but if they run regular general health checks then these should include the PSA test. Also, if men attend the GP for some other reason they should also be offered the PSA test if appropriate.

Affected Comment:

I am a Prostate Cancer survivor who only accidentally found I had prostate cancer.

I am ***** years old and diagnosed with Prostate Cancer in *****. It was ***** since I had seen a doctor and, in ***** I went to the doctor complaining of ***** He could not identify any cause for this but said, "Let's do an MOT". He found an enlarged Prostate and ordered blood tests. The first came back with a PSA of ***** and the second one came back with a PSA of *****.

At this stage I was not too worried as it was only an indication and further test were required. The doctor explained the steps but as I had no understanding of the range of PSA indicators I was not overly concerned – it was just something needed to be checked. At this stage it was only discussed with my wife.

Then an MRI scan which identified 2 lesions in the prostate. Now I was concerned. I reviewed all the literature and became anxious for the next step. I advised my 4 sons and close friends and found that Prostate Cancer was more common than I thought.

Thus followed a biopsy and it was ***** after the biopsy that I was informed that I had Prostate Cancer. Over that time, I was somewhat anxious, but the professional approach of the lead prostate nurse let me know that I was in good hands. I was advised on ***** that I had stage 1 cancer and because my PSA was ***** they offered a Proctectomy or Radiotherapy with hormone treatment and I could choose which one. Now I know what that score meant.

This naturally caused significant anxiety in me as I was not a doctor and asked to choose which treatment path.

In ***** I saw a surgeon who advised me of the steps and impact of surgery. However, I was not able to see a radiologist for ***** –So, I went to a private consultant in ***** who covered all aspects of what was offered to me and advised that since I was young enough and fit enough and that the cancers were within the margins on the prostate it was advisable to have the prostate removed before it has a chance of spreading. I am sure that this was the type of discussion had by the review board, held in ***** , which determined the treatment options once the biopsy results were in. If I had been informed of the discussion when I was told I had prostate cancer this would have significantly reduced my anxiety.

The initial experience was very harrowing for me but though out I have been incredibly supported by my wife. She has been with me through every step of the way and rightly says that she is dealing with prostate cancer as well. I have relied on her strength when time were down

Evidence Comment:

The evidence in this study is mainly from the SCHARR model and most of this appears to come from literature searches and their previous models. As stated "There are significant uncertainties in the data used to estimate the costs, harms and benefits, and the incremental NMB for each screening strategy." In the cases of uncertainty of data, sensitivity analysis should have been undertaken to identify which data elements are the most sensitive to impacting the outcomes of the models. Then one could identify which uncertainties could alter the NMB results.

On a similar note, the NMB results are not provided so one does not know how close to zero the results were.

There does not appear to be any evidence relating to screening capturing early diagnosis leading to treatment at a lower stage of cancer thus leading to reduced treatment impact on the patient and reduced cost to the NHS. The more advance the cancer the more likely treatment would be by radiotherapy, hormone treatment and other cocktails. This would significantly increase the "harm" to the patient. The data is presented with respect to the reduced number of deaths only. This makes the NMB a very blunt instrument.

The EQ-5D and associated assessment for psychological harm while gathered by surveys do not identify the source of that harm. In my case anxiety came from lack of specific personal information and lack of access to consultants within the NHS system. Is there a postcode aspect of the stress factors as to the quality of health care as well as living in an area of social depression, were these factors observed?

Regarding the harm caused by false positives and over diagnosis I cannot see data to evidence this. The PSA test is a blood sample and thus nil harm. This is followed by an MRI scan which is non-invasive that has again no harm. If lesions identified, then the biopsy can cause potential harm. Followed by treatment which will cause harm. Here I am looking for the data. We know the extent of false positive on the PSA test. There is no data of how many false positive results from an MRI scan nor after that a false positive in a biopsy.

I find the structure of the study presents the evidence in a clinical manner which does not reflect the real-life experience of the Prostate Cancer sufferers. Prostate Cancer treatments and risks are separated. The two treatments of prostatectomy and chemotherapy accompanied by hormone treatment. For the later, the treatment and risks should be considered together (chemotherapy and hormone treatment) for their impact. Combined, these two have a lifelong impact on the quality of life hence ongoing medical and social costs. This treatment is usually offered to patients who are too old or unfit for an operation or whose cancer has spread. Hence to detect Prostate Cancer earlier would reduce the harm, stress to the patient and the subsequent cost to the NHS.

The word count has severely limited my response

Discussion comment:

It is difficult to see what valid conclusions can be made from the model when "There are significant uncertainties in the data used to estimate the costs, harms and benefits" especially when the data relating to the results of the model are not presented.

Furthermore, the data is data from non-UK populations who have a different medical system and the model is based on previous treatment regimens which have been developing rapidly in the last few years.

The discussions introduce approaches pertaining to MRI scans and less invasive biopsies. While these are under development the model should be able to readily model this. Would this change the outcomes of the simulation in a positive direction or not?

The recommendations are a direct copy of the recommendation of the SCHARR report without any other considerations. Just a blanket acceptance of the model's recommendations and note that those recommendations are not supported by the provision of any resulting data of the modelling exercise. A lot was provided about the nature of the model and the input data but nothing about the output data that led to the recommendations. Hence the jump from model description to recommendations leaves a gap and the the validity of any recommendations.

In regard to the harm (and cost) caused by false positives and over diagnosis it is hard to see data on the evidence of this. The PSA test is a blood sample and thus nil harm. This is followed by a MRI scan which is non-invasive that has again no harm. If there is a lesion identified, then there is a biopsy which is invasive and can cause potential harm. The is a relative short period of time a relative safe procedure with the biopsy being the main concern. Once that is complete then Prostate cancer if confirmed or not. At this stage all false positives have been identified. No evidence (that I can see) intricates that false positives would continue into treatment.

Recommendation comment:

I strongly believe that screening should be recommended in various forms. This is based on my personal experience. It was only by chance in going to a doctor for the ***** I was accidentally found with prostate cancer. If I had not gone to that doctor, it would not be until matters got worse and the cancer more progressed that displayed symptoms would then see me at the doctor.

Looking at a testing range, I have been attending self-help groups for ***** and the majority attending are between the age of 65-75. Many of those only accidentally found they had prostate cancer and some the doctor refused to give them a PSA test, so they went to a private pharmacy at a cost of about £40. Having PSA screening would then require GP surgeries to fully support prostate screening (I gather they would expect some funding provide the subsequent referrals).

Also, the general male reluctance to avoid doctors and ignore their ailments would be minimised through screening accompanied by an effective publicity campaign to ensure a better attendance. I have friends who I suggest having their PSA checked. Some say they don't want a finger up their bum and don't realise it's a blood sample, some say because of the high false positive there is no point. However, after persistent discussion some say they are scared to know the outcome!

I would imagine with a screening the subject would just need to go to a blood centre and not have to go through their GP surgery. It could be as simple as a drop-in centre. This is far less complicated than the breast screening process and a lot cheaper.

At this stage the PSA test is the only available first step indicator that there could be an issue with your prostate. While it is inaccurate and cannot identify if a cancer is slow growing or not, it currently the only measure we have – so let's not ignore it.

Alternatives comment:

If there was not a screening programme but patients were allowed to request a PSA test (as it is now), I would suggest a much stronger media campaign to overcome males' fragile insecurities of admitting they may have something wrong with them. This would need to be well considered to overcome the impact of "Doctor Google" who can be consulted privately and offer many miracle cures and plays on peoples fears and provides misinformation to get their money.

Other comments:

It was the age of ***** is was by sheer accident that I found I had prostate cancer. I am an ***** but at the age of *****, I was not aware of the role my prostate played in my health life and live enjoyment. Let alone that the prostate also has a sphincter and on removal what role my pelvic flood would play in the game of incontinence. Additionally, that even though you would not ejaculate you could still have orgasms. This was like most men I met at the support groups and many of them said that if they could not ejaculate and some of the ED treatments were too scary

	– so are giving up sex and they don't miss it. Education, Education is the key to having men pay proper attention to their prostate health. After a year, one of the members at a support group said, "I miss my prostate". And then I thought "so do I". This prompted me to review my notes and document what a prostate does. It is quite amazing and was a best friend that I never knew I had. But I am glad we separated before the real problems started. The current model does not seem fit for purpose and building on it would only lead to compounding the problem. With the data that is available to you perhaps some of the latest technologies would provide better analysis. A controlled application of Artificial Intelligence tools should be able to rapidly provide areas for consideration and also keep up with the ever-expanding data base.
P677	Affected Comment: My Father died of Prostate cancer in *****, he was never checked, he had symptoms for some time and left it to late getting help. As a result I had annual PSA tests and in ***** was diagnosed with it. I Had successful Radical, Robotic Prostatectomy at ***** under *****. I had a successful procedure with no further treatment. Number one surgeon. As a result of my diagnoses, ***** called in my ***** and was treated with a RRP, ***** was clear and is still being monitored, *****. ***** was not called, he was *****, but has recently been diagnosed and treated for it with Radiotherapy, *****. It obviously is in our DNA and I believe all those in our category should be checked from age 50. We all get our sons to have annual PSA tests, though sadly many of the local GP doctors try to dissuade them from the test. That in itself must be stopped at GP level for we and our families who are know to be at high risk. Recommendation comment: Yes it should be recommended, because it is the largest cancer problem for men, We all know the issues with the PSA test, +/- -/+ but it must be better to have a Positive test that is then found to be negative after further checks, which are not invasive these days, rather than no

	check and it gets missed. I believe there are now more accurate tests available, Scams and Urine tests. There are 1000's of errors made with female Cervical Smears and Mama grams, but these continue. Those of us who are familiar with the subject know that not all Prostate cancers are aggressive and that many men will die before the cancer kills them. I'm sure the medical profession are quite able in this modern age to make a judgment on which cancer the patient has, aggressive or non aggressive, and treat them accordingly.
P678	Affected Comment: It has affected my husband. He was discovered to have Stage 4 Prostate cancer Evidence Comment: No connection made between the circa £20 cost of a blood test and the vast expense of treating the full blown disease. My husband's treatment has cost over £100,000 so far! Recommendation comment: It should be because it will save the country money in the long term. To reject the testing is another example of 'short-termism' which plagues this country Alternatives comment: 'Could be' or 'are' – well let's hear about them!!! Other comments: Reverse the decision immediately!
P679	Affected Comment: It has not directly affected anyone I know. Recommendation comment: Yes it should be recommended. The European Cancer Organisation has recommended that all EU countries implement prostate cancer screening, so it would be wrong the UK to fall behind.

P680	Affected Comment: My ***** and myself have all been diagnosed and treated for prostate cancer. Evidence Comment: Alongside the increased risk amongst the black population, I see no mention of increased risk amongst those of jewish ancestry. I understand their risk factors are at least as elevated as the black population. Discussion comment: I can see why selective screening makes economic sense. I had two biopsies and still have side-effects from the cancer treatment. However my cancer was only picked up after ***** years of PSA tests, diagnosed as stage 1 and revised to stage 3 after surgery. I do not know whether multi-year PSA tests are being recommended and under what conditions. It would seem that increased genetic understanding of prostate cancer and the filtering to allow slow-growing and fast-growing cancers to be identified and separated should be a top research priority. Recommendation comment: Yes but not blanket screening. I think broadly the proposals seem sensible but need to include those of jewish ancestry and also to be clear under what conditions multiple annual measurements are appropriate.
P681	Affected Comment: My father had prostate cancer and my brother in law also died of prostate cancer at the age of *****. Discussion comment: Given that the UK NSC is only in favour of screening men with a known gene variant of BRCA1 and BRCA2, why are there no recommendations for the routine genetic testing of men in higher risk groups for BRCA1 and BRCA2 variants? I believe this was routinely introduced for women in higher risk groups for breast and ovarian cancer some years ago. Recommendation comment: Of course screening should be recommended. As a ***** year old man in a high risk group, I feel that I'm unlikely to receive any testing or screening in my lifetime unless I develop specific symptoms, which is usually far too late. As age increases, treatment options also rapidly reduce. I would hope that my sons have access to effective screening before they're 50.

Affected Comment:

Open consultation on Prostate Cancer Screening.

I would like to make representations to this consultation based on my own experiences.

In ***** I was first diagnosed with Prostate cancer, more by luck than anything else. I didn't have any real symptoms except more frequent urination at night, which I put down to my advancing years.

I phoned the GP surgery and asked "could I have a PSA test?" the reply came back from the surgeries receptionist "Who said you could have that?" so I left it, clearly not going to get any joy there.

Some ***** later I was having my arm twisted regarding a *****. After a fortnight waiting to get an appointment I seen a GP who said I'll refer you on to *****. In passing I asked about getting a PSA blood test, begrudgingly she agreed.

Evidence Comment:

*****. The following day I had an appointment to see a GP in the Surgery. This was to tell me that my PSA level was at *****, following a DRE (finger up the bum) the GP told me that it looks highly likely I had prostate cancer.

An MRI quickly followed by a meeting with a Urology consultant who again gave me a DRE and said he was going to put me in for a transperineal prostate biopsy.

Again a bone scan (gamma camera) came quite quickly in my local hospital.

Followed a few weeks later by the prostate biopsy, another consultation to be told that I had ***** samples containing cancer cells. A few weeks later came a PET scan in *****. I've been lucky that the cancer hasn't metastasised to either the lymph nodes or bones.

However, on writing this *****.

Discussion comment:

I feel that having some sort of national screening programme for Prostate cancer is required, it is far too important to leave for GPs to pick up.

***** ago I was made aware of a gentleman called ***** who was known to my wife via the community of *****. My wife was made aware of ***** diagnosis, we went to see him one day, he looked well when the conversation came onto the subject of his cancer, we were thinking it had been caught early. However, ***** explained that his prostate cancer was at Stage Four. It transpires that he'd been going back and fore to the GP with various symptoms including back ache, it was only when another friend of his suggested he asked for a PSA test that he insisted on it at his GP surgery. ***** died a couple of months after this meeting.

Recommendation comment:

Another example happened to me around *****. I happened to be talking to someone, her husband was in school with me. She asked me who my GP surgery was in ***** , I told her and then she asked who was your GP there, so I told her. What do you think of him? To which I replied "not a lot!" She then replied "He killed my mother!" It turns out that she'd been going back and fore to him with various symptoms and it was only a week before she died of cancer did he bother referring her onto an Oncologist.

There are various screening programmes put in place in both England and the devolved nations, I'm specifically thinking about breast cancer screening and bowel cancer screening, with Prostate cancer being the most prominent cancer in Males and the inability of GPs to spot this, I would hope that you would reconsider having a national screening programme for Prostate Cancer.

Affected Comment:

I am one of the LUCKY ones.

Aged *****, I was LUCKY a friend suggested I needed to be tested.

I was LUCKY my GP agreed I should be tested despite having none of the usual symptoms. My PSA was ***** and I was referred to Urology.

I was LUCKY the urologist arranged an MRI scan and another PSA test. My PSA was now *****. A biopsy was arranged.

Nolonger on "watchful waiting" I was now on "active surveillance".

I was LUCKY that the Urologist believed the MRI and a second biopsy was called for which showed under sampling. Gleason score 4+3.

I was LUCKY a whole body bone scan showed the cancer had not spread out of the prostate.

I then started ***** of hormone treatment. PSA now *****.

Followed by ***** of radiotherapy. PSA now *****.

I was LUCKY the cancer had now been cleared.

Evidence Comment:

Not everyone is so LUCKY and it should NOT be a matter of luck. Too many men are dying as a result of lack of timely diagnostics and treatment.

Not just one PSA test but a series over time.

MRI is more accurate than biopsy and has fewer side affects.

Discussion comment:

I don't think there would be over diagnosis. More men would survive cancer.

I don't think there would be over treatment if MRI is used instead of biopsy.

Recommendation comment:

Screening should be recommended but then it is up to the individual to decide whether to follow a particular treatment plan.

Alternatives comment:

How do you know you have the condition until you are tested?

There is plenty of information out there from prostatecancer.uk etc to help understand the condition and treatment paths. This just needs to be promoted to make men more aware.

Other comments:

	Don't just rely on LUCK.
P684	Affected Comment: I was diagnosed with prostate cancer in ***** as a Gleason 3 plus 4 and treated with radiotherapy and hormones achieving a succesful outcome. This was achieved by a PSA that scored ***** , a follow up that was also ***** and then an MRI and biopsy. I consider that this removed the issue of false positives and should be offered to all men with a history of prostate cancer in brother or father and high risk groups such as men of African origin. I consider myself lucky as I had a ***** that didn't fit the profile suggested by NHS as likely indicator of cancer. Routine monitoring would have picked it up. Evidence Comment: I simply cannot understand why the NHS suggestion for seeking advice would tend to mean the diagnosis would be too late to allow for a cure. An organisation like Prostate Cancer UK is a responsible campaigner and is clear about the need for routine monitoring. Given that a man dies every 45 minutes from this condition it seems the height of negligence to ignore it in this way. I think there may be a gender discrimination issue here given the efforts and monitoring applied to breast cancer for women. There is simply not enough investment in finding a better form of testing which leaves the worrying possibility that men's lives are undervalued Discussion comment: See above Recommendation comment:

	See above Alternatives comment: At the very least the NHS should routinely notify every close male relative of a person diagnosed with prostate cancer and carry out regular screening. My brother had prostate cancer but the NHS did not suggest to him that he let me know or make any effort to contact me Other comments: Once in the system the treatment I received was exemplary. The issue here is to identify the condition early and the NHS advice and interest falls far short of achieving this
P685	Affected Comment: I HAVE STAGE FOUR ADVANCED PROSTATE CANCER Discussion comment: UNTIL I WAS DIAGNOSED i KNOW NOTHING ABOUT PSA TESTING. I KNOW IT IS NOT PERFECT, BUT IN MY CASE (AGED ***** AT DIAGNOSIS) WITH A STARTING PSA OF ***** IT WOULD HAVE SET THE SCENE FOR FURTHER INVESTIGATIONS AND TREATMENT BEFORE IT BECAME SO SERIOUS. Recommendation comment: SCREENING SHOULD BE RECOMMENDED. ALTHOUGH NOT PERFECT REGULAR SCREENING WOULD ENABLE FURTHER INVESTIGATIONS AND TREATMENT BEFORE IT HAD PROGRESSED TO THE MORE SERIOUS LEVEL. Other comments: AT THE VERY LEAST PSA LEVELS SHOULD BE MEASURED AS PART OF REGULAR BLOOD TESTS FOR OLDER MEN.

Affected Comment:

I was diagnosed with Prostate Cancer in ***** following a PSA blood test with follow-up CAT Scan and MRI scan to confirm diagnosis. I had Radical Prostatectomy in *****. Post-operative histology confirmed a Grade 6 cancer with no signs of metastasis. Since then I have had no further treatment. I was advised to have regular PSA tests annually for life and since the surgical operation ewveryone for the last ***** has been less than *****. I am therefore 99.9% certain I am totally clear of the cancer,

At the time of the original test I felt completely fit and well and had no idea of any problems, the test was at a 'walk-in' clinic I visited on the spur of the moment. I am convinced that if I had not been tested until there were any symptoms it would have spread out of control and been too late to be cured and I would probably have been dead about *****!

Discussion comment:

The conclusions are very short-sighted and based on the fact that it picks up false positives, forgetting that it also picks up true positives such as in my case, having already agreed that there is no better test yet. No treatment would ever be started from this one test alone and further tests would show up the false ones to be discarded, having confirmed the true ones. It is ridiculous to say that further tests could cause 'harm'.

The final comment that there is no single treatment for early-stage is complete rubbish and I am living proof that early treatment is VERY worthwhile.

Recommendation comment:

Ultimately there will probably be a better method of testing for Prostate Cancer, but the screening committee has admitted that PSA testing is the best there is for now. It is futile to state that just because it might upset some men to be told, falsely, that they may have prostate cancer, we should disregard the 26% of men who are developing Prostate Cancer and not bother to help them until it is too late for full recovery.

Even in the cases of men developing very slow-growing cancer which may not cause problems, knowing that it is present means that it can be monitored in case of future flare-ups, even if they will probably need no treatment.

Alternatives comment:

You have already admitted that "there is not enough evidence at present to show that there are better tests than PSA" so this question is irrelevant.

PSA testing is not perfect but if it is the best means of testing for the present it should be adopted without fail and only faded out when it can be replaced with something better.

Other comments:

Screen for Prostate Cancer by PSA testing until something better omes along – it was PSA testing that saved my life and I have many personal reasons to be grateful that it lead to my treatment and saved my life!

P687	Affected Comment: This condition has affected me. My prostate cancer was only picked up when a friend advised me to be tested. My friend had metastatic prostate cancer which was picked up too late and sadly he is no longer alive. I had no symptoms at all that anything was wrong and yet when I was tested it got picked up that I had prostate cancer which I am still being treated for. Recommendation comment: Screening should definitely be recommended as other men that do not have symptoms but have prostate cancer will be screened in time to get the relevant treatment for a positive outcome.
P688	Affected Comment: Diagnosed with stage 4 prostate cancer at ****. Gleason 9, grade 5 No BRAC/angelina jolie gene Proactive testing would have saved my life Evidence Comment: The men who are dying due to not testing Recommendation comment: Should be recommended so other men don't have to die early like I will

Affected Comment:

I was diagnosed with Prostate Cancer on ***** aged *****.

My ***** had suffered ***** and my ***** developed prostate cancer later in life and was treated with targeted radiotherapy. As advised by my ***** , I had annual PSA checks from the age of ***** – my levels hovered around ***** but had started to rise slightly.

***** I went to see my GP with ***** and no other symptoms. The doctor noticed the rising PSA and undertook a prostate examination. I underwent a template biopsy under general anaesthetic, which showed that I had prostate cancer with a gleason score of 3+4 and the tumour was T3A, contained within the prostate, but nudging the outside wall. In ***** I had radical prostatectomy. My physical recuperation wasn't too bad. I had learned the Pelvic Floor exercises in the period leading up to the operation, and was probably 'dry' without the use of pads within a very short space of time. A lot of men don't ever recover from urinary incontinence. What was bad was the erectile dysfunction, which I never really recovered from despite ***** . This was devastating and in some respects you never really get over it.

I continued to have regular PSA blood tests and in ***** my reading was *****.

Over ***** I suffered ***** but despite several GP and hospital visits and ***** , nothing really helped.

In ***** , whilst holidaying in ***** , I experienced ***** and attended ***** for help. They ran a series of tests, including a CT scan and confirmed that the prostate cancer had returned. The urologist said that I should return home and he would refer me to the *****.

In the following ***** my condition worsened. I attended ***** was given various treatments without being referred to a cancer hospital. Eventually I was told that I was not in the ***** catchment area. Fortunately ***** agreed to see me urgently. They ran a series of tests, a CT scan and a Nuclear Scan (Pet). I was diagnosed with Stage 4 Prostate Cancer, PSA of ***** , with metastases to my lymph nodes and skeleton. I am classed as treatable but not curable. I was immediately placed on hormone treatment for life. I have had ***** , and a range of medication including ***** . My bone pain is severe, so I take ***** . I have *****.

Evidence Comment:

I do not feel that the impact of high risk groups is fully recognised. I have heard of a fair few friends both high risk groups who have been denied PSA checks by their local GP, and have only been given checks when they have insisted. I am also concerned about the children of men with prostate cancer and at what age they should be tested. ***** carried out a BRCA blood test on me and confirmed that I do not carry that gene, What does this mean for my sons? If I hadn't had PSA blood tests from the age of 50, I most probably would have been dead long before now. The cancer in ***** was nudging the wall of the prostate, I had no symptoms, and wasn't carrying the BRCA gene.

Discussion comment:

I believe that the rate of late diagnosis is rising because not enough screening is taking place. I think that regular screening of men in high risk groups is vital. The result of not doing so leads to far too many suffering from advanced prostate cancer, with the devastating effect that has on

	the lives of those men and their families. This also increases the added cost of prolonging the lives of these men with more costly treatments later on. Recommendation comment: I do not believe that we need to have screening across the nationwide population. Black men and men with a family history have long been neglected by the system. I also think that statistics of men with prostate cancer, and advanced prostate cancer should be captured. I believe the risks of overdiagnosis and overtreatment to be manageable – initially with a watching brief and follow up PSA tests for an upward trend before treatment. Alternatives comment: There definitely needs to be organised prostate testing instead of the ad-hoc testing that exists at present. GP's need to be consistent in offering and encouraging PSA testing when required. Education should be improved to give better guidance to all men about the risks of not taking up PSA testing. I believe that specialist Urology units should exist in each Hospital group, like the excellent unit that exists in *****. Other comments: I think that it is important to keep the policy under active review to take account of new evidence, methods and treatments that come to light. We need to take account of the expertise of Consultants in this field who have day to day experience of CT and Pet scans and treatment methods. I UNDERSTAND THAT SCREENING DECISIONS ARE COMPLEX, BUT I WANT MY LIVED EXPERIENCE TO BE CONSIDERED ALONGSIDE THE CLINICAL EVIDENCE
P690	Affected Comment: It has impacted my Father. Evidence Comment: I had an annual blood test and still think it is wise each year to do so regardless of the validity of the results. Discussion comment: Non at this time. Recommendation comment: Yes to offer it as it is not too onerous and it is nearly a first step amongst further checks which which could be undertaken. Alternatives comment: To find a more accurate initial blood test or add another supplemental check or indicator perhaps. Other comments:

	Not at this time and I await the outcome of the review.
P691	Affected Comment: Yes I was diagnosed in *****, aged *****, following a PSA test result above 6 and a biopsy which showed spread to a pelvic lymph node. I had insisted that my GP request regular PSA tests in ***** as my ***** had prostate cancer. In my***** the test were once or twice a year, and ***** two or three times a year. There was a sizable jump in my PSA level from about ***** to over ***** over a ***** period which triggered referral. I subsequently had ***** of radiotherapy and ***** of hormone treatment and am currently in remission. Evidence Comment: Although the evidence is clear that single PSA tests are unreliable, I would like to have seen any evidence for the efficacy of a series of regular testing for those with a family history of the disease. For example, twice a year for 50+ men whose father had been affected by the disease. Such a trend line would not only allow the natural variation in PSA levels to be exemplified but would also make it clear when a discontinuity occurred which would then be confirmed with an immediate retest. Discussion comment: I disagree with the conclusion in the light of my comments above. A biopsy and possible MRI would only be triggered by a confirmed jump in the PSA level for men with a family history. This would therefore allow good targeting of specialised tests and minimise unnecessary and uncomfortable procedures. Recommendation comment: Yes I think there should be regular screening for men aged 50+ whose father had been diagnosed with prostate cancer. The optimum frequency would need to be established through analysis of the data; my example of every ***** worked well for me. Alternatives comment: I think further help should be properly considered around enhanced screening as described above,

	Other comments: No
P692	Affected Comment: It has affected me Recommendation comment: 100%. There may be some men for whom treatment could cause side effects unnecessarily, such as ED and incontinence. However, currently around 12,000 men are dying unnecessarily because their diagnosis comes too late. Is it right to continue sacrificing so many men simply to spare a minority suffering the side effects listed. Currently, the estimate is that 5,000 men are over-treated. So for every man that has impotence or incontinence (and, of course, not all will have these side effects), more than 2 are dying. This cannot be an acceptable trade-off.

Affected Comment:

Yes, prostate cancer has had a profound personal impact on me. I lost a ***** to the disease at the age of *****, shortly after his marriage. His diagnosis came late, and the aggressiveness of his cancer was a devastating reminder that although prostate cancer is usually associated with older men, younger men can also be affected in rare but severe ways. In addition, through my research and community engagement work on prostate cancer, I have met many remarkable men living with the disease. Their experiences, ranging from the challenges of diagnosis to the emotional and physical impact of treatment, have shaped my understanding of both the burden of the condition and the importance of improving detection and care. These personal and professional experiences strongly inform my engagement with the consultation and reinforce my belief in the need for continued progress in early detection and management.

Evidence Comment:

The committee is commended for the substantial time and expertise invested in reviewing the available evidence and developing these recommendations. Overall, the evidence base considered appears comprehensive and appropriate, drawing on large, randomised trials, long-term follow-up studies, and economic modelling to assess the balance of benefits, harms, and costs associated with prostate cancer screening. The inclusion of recent updates from the CAP and ERSPC trials, including extended follow-up data, is particularly welcome and provides important reassurance that the modelled estimates of overdiagnosis and mortality reduction are broadly consistent with observed outcomes. The explicit discussion of uncertainty around natural history, disease progression, and PSA test performance is also appropriate and reflects longstanding challenges within prostate cancer epidemiology. That said, several areas merit further consideration as the evidence base continues to evolve.

First, while the focus on BRCA1/2 mutations is justified given the clearer evidence of increased risk and potential net benefit, emerging evidence suggests that other genetic variants may also confer elevated risk. As polygenic risk scores and broader germline testing become more embedded in clinical practice, future reviews may wish to consider whether additional genetic markers could be incorporated within a more refined risk-stratified screening framework.

Second, although family history is included as a potential risk group, the review appropriately acknowledges the limitations of existing data. Family history is often poorly captured in routine healthcare records, and many individuals are unaware of its relevance or accuracy. As such, the evidence supporting family history as a standalone basis for organised screening remains weak. Continued efforts to improve the systematic collection and interpretation of family history data would strengthen future modelling exercises.

Third, while the review discusses ethnicity-related risk, the available UK-specific evidence on stage at diagnosis, disease aggressiveness, and survival outcomes among Black men remains limited. Much of the evidence informing assumptions around tumour grade and progression is derived from non-UK populations, particularly the United States, where healthcare access and diagnostic pathways differ substantially. This limits confidence in the transferability of some assumptions and highlights the importance of generating robust UK-based data. Finally, the review rightly notes that newer tools such as risk-adapted PSA thresholds, MRI-first pathways, and biomarker-based triage tests were not fully incorporated into the model due to data limitations. While this is understandable, these developments will be important to consider in future updates, particularly if they offer meaningful reductions in false positives or overdiagnosis.

Overall, no major bodies of high-quality evidence appear to have been omitted. However, continued investment in UK-specific epidemiological, genetic, and outcomes research will be essential to reduce uncertainty and inform future screening policy.

Discussion comment:

The discussion and conclusions presented by the committee are balanced, transparent, and aligned with established screening principles. The acknowledgement that some stakeholders may find the conclusions disappointing is important, particularly given the high public and professional interest in prostate cancer screening. Nonetheless, the reasoning underpinning the recommendations is clearly articulated and grounded in the available evidence. The recommendation to offer targeted screening to men with a known BRCA gene mutation appears appropriate. This group demonstrates a clearer risk profile, a higher likelihood of clinically significant disease, and a more favourable balance between benefit and harm compared with the general population. The committee's cautious framing, including recognition that the feasibility and costs of identifying BRCA carriers were not fully modelled, is also welcome.

The decision not to recommend screening based on family history alone is similarly justified. While family history undoubtedly confers increased risk, its inconsistent recording and variable interpretation limit its utility as the basis for an organised screening programme. In this context, existing guidance encouraging informed discussions about PSA testing between men with a known family history and their GP appears proportionate and sufficient at this stage.

The most challenging and sensitive recommendation concerns targeted screening for Black men. While Black men in the UK have a higher lifetime risk of prostate cancer, the committee appropriately distinguishes between increased incidence and evidence of benefit from screening. UK data do not consistently demonstrate later stage at diagnosis or poorer survival among Black men, and emerging evidence suggests that survival outcomes may be comparable to, or in some cases better than, those observed in White men. These findings challenge long-held assumptions and are highly relevant to screening policy.

The discussion also rightly highlights concerns regarding PSA biology and test performance. Higher baseline PSA levels among Black men, independent of clinically significant disease, raise the risk that uniform PSA thresholds could generate disproportionately high false-positive rates, leading to unnecessary investigations, anxiety, and harm.

Overall, the committee's conclusions reflect a careful weighing of evidence and uncertainty. The emphasis on further research, particularly through large UK-based prospective studies such as TRANSFORM, is appropriate and necessary before revisiting recommendations for targeted screening in Black men.

Recommendation comment:

On the basis of the current evidence, prostate cancer screening should not be recommended for the general population or for Black men as a targeted group. This position is consistent with both the findings of the economic model and the core principles of screening, which require clear evidence that benefits outweigh harms at a population level.

For men with confirmed BRCA gene mutations, a targeted screening recommendation is reasonable, provided it is implemented cautiously and accompanied by clear communication about potential harms, uncertainties, and the limitations of the evidence. Even within this group, screening should be viewed as an evolving policy area rather than a settled intervention.

Arguments in favour of targeted screening for Black men often implicitly assume that uptake would be sufficiently high and equitable to deliver population-level benefit. This assumption is optimistic and not well supported by evidence from existing screening programmes. Uptake across established national screening programmes remains socially patterned, with lower participation among minoritised ethnic groups and those experiencing socioeconomic disadvantage. There is little reason to expect prostate cancer screening, associated with invasive diagnostic procedures, uncertainty, and potentially life-altering side effects, to achieve higher or more equitable uptake.

In addition, historical and contemporary experiences of discrimination have contributed to mistrust of healthcare systems among some Black communities. These factors, combined with gendered barriers to preventive healthcare and stigma surrounding prostate cancer and its treatments, are likely to limit engagement with screening. Low or uneven uptake would reduce effectiveness while concentrating harms among those who do participate.

Given that fewer than 10% of cancers in the UK are currently diagnosed through screening, it is unlikely that introducing prostate cancer screening would substantially improve the detection of clinically significant disease. There is a real risk that such a programme would divert resources, exacerbate diagnostic bottlenecks, and widen inequalities by preferentially benefiting more health-engaged individuals. From an equity perspective, greater benefit is likely to be achieved through improving symptom awareness, timely presentation, and access to high-quality diagnostic pathways, rather than introducing a screening programme with uncertain uptake and unclear net benefit.

In conclusion, the committee's recommendation not to introduce population or ethnicity-based prostate cancer screening at this time represents a proportionate, evidence-based response to uncertainty and appropriately avoids the risk of unintended harm. Continued monitoring and research will be essential to ensure that future recommendations evolve in line with a strengthening evidence base.

Alternatives comment:

There are several ways the NHS and the government could better support people affected by prostate cancer, beyond a formal screening programme. A major priority should be significantly strengthening public awareness of risk factors, particularly age, Black ethnicity, and family history, and the benefits of early diagnosis. Many men do not recognise their own level of risk, and targeted campaigns could help improve understanding and prompt earlier help seeking.

GPs should also be supported and empowered to initiate conversations about prostate health with men at higher risk by raising the topic proactively during routine consultations, explaining the potential benefits of early detection, and having honest, balanced discussions about the limitations of current tests and the possible side effects of treatment. Improving the confidence and capacity of primary care to engage in these conversations could help many men make informed decisions well before symptoms appear.

Efforts to reduce inequalities in awareness and access, particularly for Black men and underserved communities, would also make a meaningful difference. Clearer pathways, culturally tailored information, and community based outreach could help ensure that the people most at risk receive timely guidance and support.

Crucially, achieving these goals will require improved funding for research. This investment would allow the NHS and government to develop and evaluate more effective public health interventions, refine diagnostic tools, and generate robust evidence to inform policy decisions.

Strengthening research capacity alongside awareness and primary care engagement could transform outcomes, even in the absence of a national screening programme.

Other comments:

Invest in research on digital tools and clinical workflow strategies to accurately capture, update, and use family history information across primary care.

Provide training and guidance for GPs to bring up prostate health proactively with men at higher risk (e.g., by ethnicity, family history, genetic risk).

Invest in awareness campaign initiatives.

Affected Comment:

I am a *****.

As a ***** I was responsible for the diagnosis and treatment of numerous men with prostate cancer. Also, as a previous member of the ***** , I was involved in the design, conduct and oversight of national and international trials of prostate cancer treatment for many years.

Since retirement in ***** I have spoken with many men diagnosed with prostate cancer at ***** , a charitable cancer support centre ***** , Here, I learn frequently of the impact of PSA testing, and prostate cancer treatment, on men's lives and that of their families.

Although I oversaw the introduction of PSA testing in the ***** this was for the monitoring of men known to have prostate cancer, not for the screening of asymptomatic men. Aged ***** years, having kept up to date with the outcomes of ongoing research I have never had a PSA test. At this age I know that there is a 50% chance that I am sitting on cancer in my prostate as I write but am not concerned nor do I plan to be tested.

Evidence Comment:

The UK NSC has given due consideration to the relevant data. The only possible omission is the latest, albeit very limited, data concerning a possible link between prostate cancer and the Lynch Syndrome.

In recent months I have met with several women with breast cancer who have demonstrated the genetic mutations associated with Lynch syndrome but have experienced difficulty in obtaining further relevant genetic testing for themselves and their children.

Previous research has suggested that Caucasian men who are members of a Lynch Syndrome family and demonstrate MMR gene mutation (particularly MSH2) have a 2 to 3 fold risk of developing prostate cancer even if they have had no prior colon cancer [Ref 1]. More recently a prospective study has confirmed that carriers of MSH2 and MSH6 pathogenic variants had a higher incidence of prostate cancer compared with age-matched non-carrier controls[Ref 2].

Given the anxiety of parents who have the Lynch syndrome for their children's future wellbeing access to appropriate genetic testing for their sons as well as daughters should be provided in the context of prospective study.

Refs. 1. Ryan S, Jenkins MA & Win AK. 2014. "Risk of Prostate Cancer in Lynch Syndrome. A Systematic Review and Meta-analysis." Cancer Epidemiol Biomarkers Prev 23 (3): 437–449. 2. Bancroft EK et al., 2021. "A prospective prostate cancer screening programme for men with pathogenic variants in mismatch repair genes (IMPACT): initial results from an international prospective study. "The Lancet Oncology: 22;11 pp.1618-1631.

Discussion comment:

I agree with the conclusions and recommendations of the UK National Screening Committee.

I also suggest that the proposed targeting of men with confirmed BRCA 1/2 gene variants should be extended to include the genetic testing of male members of Lynch syndrome families.

However, it is not clear what consideration has been given to the subsequent management of those men found to be a higher risk of prostate cancer.

For BRCA positive women at risk of further breast cancer the possibility of double mastectomy is undoubtedly daunting but often welcomed. For young men (45-61years) found to be carrying the relevant gene mutations the consequences are more complex. The options available for pre-emptive treatment – radical prostatectomy, radiotherapy and hormone therapy – all carry significant risk of life-changing unwanted side effects. Adequate opportunities for proper, in depth, discussion and psychological support should be made available.

Collaboration with the TRANSFORM trial is worrying. The need to evaluate MRI scanning is obvious but the design of this trial is flawed.

Given the extent to which PSA testing of asymptomatic men has been discredited (and national screening rejected) “current practice” and randomisation to PSA testing as a control arm is entirely inappropriate. Given the harms accruing from PSA testing, its inclusion in the study should be considered unethical. To ensure the long term validity of the trial's outcome and minimise potential contamination the control arm should comprise men who have no PSA testing.

Recommendation comment:

Screening for prostate cancer using PSA testing should NOT be recommended.

I am well aware that numerous members of the general public will support the suggestion of a screening programme but they do so in ignorance, influenced, also, by the extensive misinformation in public media.

It has become a regular feature of public debate to state that “Early diagnosis and early treatment of cancer saves lives”. While that appears to be true for some cancers, such as cervix, bowel, testis and bladder, it is not true for prostate cancer. The largest trial of PSA screening, the Cluster Randomised Trial of PSA Testing for Prostate Cancer (CAP trial) led by Bristol University [Ref 1] concluded “while PSA-based screening increases the detection of low-risk prostate cancers, it does not save lives.” [Ref 2]

The European Randomized Study of Screening for Prostate Cancer (ERSPC) concluded that the chance of being alive 23 years after PSA screening was 49.8% compared with 49.6% in the unscreened men. Furthermore, 27 men per 1,000 screened were over diagnosed, as a result of which 2,103 men would have undergone unnecessary treatment, many of them suffering life-changing side effects[Ref 3].

If these were the results of research for a potential, new anti-cancer drug no pharmaceutical company would invest in further development, nor would NICE contemplate its introduction to the NHS. For the same reasons no other country in Western Europe has commenced a prostate cancer screening programme.

For reasons that will now be apparent the National Screening Committee has advised that the NHS should not introduce a national PSA-based screening programme for prostate cancer. While such decisions are eventually to be made by government it would be foolish in the extreme to ignore the evidence-based conclusion of the National Screening Committee.

References. 1. Prostate-Specific Antigen Screening and 15-Year Prostate Cancer Mortality: A Secondary Analysis of the CAP Randomized Clinical Trial. JAMA 2024; 331(17):1460-1470]. 2. The CAP and ProtecT trials -University of Bristol; <https://www.bristol.ac.uk/cancer/research>. 3.

	European Randomised Study of Screening for Prostate Cancer – 23 year Follow-up. N Engl J Med 2025; 393:1669-1680. Alternatives comment: In the continuing absence of a national screening programme for prostate cancer three actions are needful. 1. Members of government should desist from supporting PSA testing. When speaking in public they should not repeat the misleading mantra that screening/early diagnosis of prostate cancer saves lives. Instead they should be clear in their support for the NSC conclusion. 1. All men contemplating a PSA test should be adequately informed of the relevant factual evidence and be in a position to make a truly informed decision. From personal experience, explaining in plain English and answering questions requires at least half an hour of personal conversation. As few GPs in today's overburdened NHS have the time to provide such a consultation an alternative, effective means of informing men (and their wives) of the pros and cons of PSA testing needs to be developed. 2. Most important is investment in new research to identify more effective forms of treatment for prostate cancer, whenever diagnosed, that are not associated with life-changing unwanted side effects. Other comments: No.
P695	Affected Comment: My father and brother in law have both had prostate cancer Recommendation comment: Absolutely, surely catching this early is far more cost effective than treating the outcome

P696	Affected Comment: The condition has affected family and family of friends. Evidence Comment: The evidence did not robustly consider the evidence from other countries, such as Sweden. A targeted approach, with health inequalities at the fore front, using minimally invasive screening techniques, is the way forward. Focus on those most at risk (black men, those experiencing more health inequalities), do a PSA test, give them an MRI if the PSA comes back positive, offer a biopsy if the MRI results show it may be necessary. Be evidence led, use the information already available from places which are trialling these screening approaches. Discussion comment: The recommendation is flawed. Men should be offered screening – PSA, MRI, biopsy, as clinically indicated. Recommendation comment: Screening should be recommended. As above, follow the evidence from other countries. Otherwise, you are leaving men at the mercy of luck as to whether their disease is caught at a potentially treatable stage. Not screening will cost the NHS and people's health, wellbeing and lives. Alternatives comment: Implement the screening programme. Focus on health literacy and give quality, accessible, information, available in multiple formats, about what to expect. Other comments: Evidence base is key. Work from the available evidence. Implement the PSA – MRI – biopsy screening. Or you're jeopardising men's health, to the whim of luck.
P697	Affected Comment: Yes. Fortunately it is most likely that I will die with it rather than of it. I am just *****! Evidence Comment: While the primary focus may be on screening, there is a case for support for those people diagnosed who are undergoing treatment. It is fatal in some cases and some treatments may be painful. Discussion comment: None Recommendation comment:

	Yes as they may be not only a preventative but also cost-saving in terms of treatment. Alternatives comment: Support for those undergoing treatment. Other comments: None
P698	Affected Comment: Yes I was diagnosed with Prostate cancer ***** ago Evidence Comment: no Discussion comment: I am of the opinion that the committee is wrong Recommendation comment: yes definitely screening for all males over 45 should take place to ensure the cancer is not in an advanced stage Alternatives comment: I do not think at this time there are any other alternatives at this time to more screening Other comments: no

Affected Comment:

Having had prostate cancer myself I find it worrying that there is no screening program for this. I was diag purely by chance as I did not go to my GP for my prostate I went for *****. I was lucky that this was found by a DRE and the GP felt my prostate was enlarged. I now have annual PSA tests to check my levels.

I volunteer for the *****. My group of ***** including myself and all of us have either had prostate removal surgery or being treated and not a single one of us went to our GP for our prostate. Testing on an annual basis would pick up prostate issues and also lead to less invasive procedures being carried out.

Evidence Comment:

My diagnosis was caught by accident not by a programme of testing. Of my group of male friends who all have had prostate issues not one went for this and were diagnosed by chance.

Discussion comment:

Women are tested for breast cancer and have cervical smears, men have nothing. Prostate cancer kills one man every 15 minutes in the UK and this can be prevented by testing. It's a simple test and we should be called for this not have to demand a test.

Recommendation comment:

Yes I do, men are notorious for not going to the GP by choice and suffer in silence. Screening would ensure men are called rather than having to request. It will save lives as this condition has no symptoms until it's too late. This results in surgery and invasive procedures.

Alternatives comment:

The NHS needs to make this easy to use. Screening programmes help to inform and catch early.

Other comments:

No, screening is essential for prostate cancer and my consultant was asked why more men have prostate cancer are being treated responded with the following.

We have better detection and resolutions.

P700	Affected Comment: I am a prostate cancer survivor, who has setup a support group for men. I also have ***** who are diagnosed with prostate cancer b Evidence Comment: I urge the National Screening Committee to do more to improve the evidence base for Black men by supporting the analysis and publication of real-world evidence, and reevaluate prostate cancer screening in Black men as soon as new evidence is available. Prostate Cancer UK is undertaking research to fill in these evidence gaps, and will be formally requesting the UK NSC to use the findings of this research to update the model as part of the consultation process. Discussion comment: Failing to have a screening programme means that more men are being diagnosed late. This in turn means that their options for treatment are reduced. In my group we have men are hormone treatment for several years. This costs a considerable sum, when considering how many men across the country are on this pathway. Men on hormone therapy suffer physical and mental anguish. This can and should be avoided. A screening programme will save more of the man and their lives. Recommendation comment: As stated above. A screening programme will save more of the man and their life. Alternatives comment: A screening programme combined with a well man/health and wellbeing checkup for men is the way to go. Men are notoriously bad at visiting a GP. They see it as a badge of honour not to have visited for years. We have to change that dial. Screening will also save the cash-strapped NHS money over the medium to long term
P701	Affected Comment: I am a person with Lynch syndrome – the MSH2 mutation. Prostate cancer affects many of us as a community, however I haven't been directly impacted by prostate cancer. Evidence Comment: I believe evidence was missed. 25% of men with the Lynch syndrome MSH2 mutation will get prostate cancer according to the PLSD. According to the IMPACT study from ICR, men with the MSH2 gene fault more often had aggressive, potentially life-threatening tumours, with 85 per cent showing 'clinically significant' disease, compared with no non-carriers. This suggests over diagnosis in MSH2 carriers is unlikely. Discussion comment: Yes – people with Lynch syndrome appear to be missed. I can't find any mention in Lynch in any of the documents. Lynch syndrome is as common as BRCA 1/2, at significant risk of PCa, and

	seemingly aggressive PCa. Please consider us alongside those with BRCA 1/2 as you finalise your recommendations. We are like sitting ducks. Recommendation comment: Should not be for the general public. Should be for the highest risk groups – to which I would add to your recommendations certain groups with Lynch. Alternatives comment: Better communication. Other comments: Please simply consider the evidence available for people with Lynch syndrome. It is a frightening thing to live with a condition like this, and you feel much more secure if you are being watched. This isn't only about feeling more secure. There are ~300,000 of us with Lynch in the UK (diagnosed and the vast majority undiagnosed) and there is evidence to suggest targeted screening for at least some of us for prostate cancer would be appropriate. I look forward to your response. Thank you
P702	Affected Comment: I was diagnosed ***** at the age of ***** with Prostate Cancer with a Gleason score of 7. This followed a rise in my PSA level following a test that I asked for through my GP. There is no family history of prostate cancer but since being told in ***** that I had an enlarged prostate I had asked for a PSA test as part of my annual check up. Once it was diagnosed I made sure that my ***** have been made aware of the added risks they now face. Evidence Comment: As a member of the public I cannot comment on the technical aspects of the review. But I do wonder how much evidence was taken from those who have been diagnosed and those cleared and what weight such views were given. Discussion comment: It seems to me from the people I met during my treatment and socially that I feel lucky that I took the action to get regularly tested which I am sure detected my cancer at a relatively early stage. Many of the men I met had higher Gleason scores and more aggressive cancers despite some being younger than me. They had only had a test once issues had been arisen. I firmly believe that if there had been a screening programme for men over say 50 those fellow patients would have had an earlier diagnosis and the chance of a better outcome. There are high risk groups of men in society and to fail to implement a screening programme for them is in my view a great mistake. Recommendation comment: I think screening should be implemented for all men rather than relying on personal initiatives. The diagnostic process for me was a path of PSA test, referral to a consultant, MRI scan, a

	rectal examination and then a biopsy. It was clear after the first three stages that I had a cancer and the next two were simply confirming the scale and seriousness of the problem. A screening system which followed that path would not produce any outcome that was intrusive before the broad diagnosis and would benefit many men. Alternatives comment: If there is not to be a blanket screening system then at least there should be a programme that targets men at higher risk due to their ethnicity or family history of the disease. At the very least there should be a decision to encourage men to get tested and make it easier for them to access tests. The costs for men and their families of the current system is very high and would far outweigh the costs of a proper system of diagnosis. Other comments: I would hope that the treatment pathway for men diagnosed with prostate cancer nationally is as good as the one I was able to follow in *****. The treatment options must be good but again would be improved by early diagnosis. I also think that this must be decision which is kept under frequent review and that those reviews must pay more attention to the views of patients and their families who bear the brunt of the failings of the current system or rather the lack of one. I say this because we know better than anyone the issues that arise as we live with them. It is not simply about the technical factors but the human experience.
P703	Affected Comment: I was diagnosed with PC in ***** purely by accident and thankfully my cancer was discovered early so was treated successfully. Evidence Comment: I do not understand why they will not institute a screening program. My friends cancer could have been diagnosed sooner had there been one, unfortunately his cancer was diagnosed late and he is living with untreatable cancer as a result. Recommendation comment: Screening should be recommended for all men over 50 especially for men who are either black or have a family history. Alternatives comment: Just have a screening program and stop worrying about the costs.

P704

Affected Comment:

I was diagnosed as having stage T3a aggressive prostate cancer in ***** by chance following a general check up blood test that if requested mainly to check on my ***** as there's a history of *****.

The disease was only spotted because my GP suggested as a routine thing that I had a PSA check as part of the blood test. I had absolutely no symptoms of prostate cancer or history of prostate cancer in close male relatives and it was purely because of my age that my GP suggested it.

As it turns out this was a blessing in disguise as I was able to be treated with radiotherapy before the cancer had metastasized, which it almost certainly would have done if left untreated given the aggressive nature of it.

I can see no reasonable reason for there not to be a national screening programme for what is the biggest cancer killer of men. With developments in the ability to screen for the disease with less false positive and false negative results it seems to me that we should be screening for this disease.

Whilst I understand the benefits of supporting people with other health issues like obesity (where there seems to be a lot of money spent) due to the multiple issues and medical conditions this can cause to some extent obese people have an element of control over their weight whereas prostate cancer sufferers have none. On this basis alone the funding of some areas of health support could/should be redirected to improving early diagnosis of prostate cancer.

Affected Comment:

I have had prostate cancer and treatment that, to date, has been successful. *****.

I had regular PSA testing pre-Covid, until our local health area ***** changed policy. I was told in ***** when I asked for a test that this was not available without GP consultation (despite having it for *****). I insisted and after a very assertive approach to my local surgery where on my ***** visit I refused to leave until the receptionist typed a letter onto my GPs email holding, up a large and angry queue, quite out of character for me, was eventually granted a GP appointment 'with nothing wrong with me'. My GP was actually much more receptive to my plea for a test. Even though I had completed ***** before, I just felt that I was the age when I needed to keep the testing routine going.

My PSA was not actually very high on re-testing, but it had jumped from its previously average level, and at this stage my GP did take action, with a digital rectal examination, and putting me on the two week wait for cancer diagnosis services.

Unfortunately, those services had a long waiting list in my area, and after a period of ***** , and with declining ***** , I entered the private system. An MRI revealed early stage prostate cancer, confirmed with a biopsy and then prompt surgery. It cost around £25,000.

BUT what if I wasn't assertive enough to hold up the queue in the surgery to demand action? Or I hadn't got the money? My MRI on the NHS did come through within ***** , but there would have been wait for biopsy. My condition may well have deteriorated in that time. I may well not have the good health I now enjoy, I ***** , and if diagnosed later would have cost the NHS several multiples of the treatment I had.

Evidence Comment:

I would not be so bold as a layman.

But I would comment that some of it seems out of date. The PSA test does remain in the diagnostic path, but even the person in the street knows that this is no more than an indicator for further testing with the advent of high quality, lower cost MRIs. It seems that the evidence 'hides behind' the PSA test as THE test that can lead to overtreatment. So I think the balance of the evidence is wrong. It should look at the last 12-24 months and see if the advent of MRIs in the diagnostic path have resulted in more accurate diagnosis without the potential harm of biopsy. All the men I know in my prostate support group are having an MRI before any potentially harmful action is taken. So PSA might stay in the screening process, but screening might be through the newer lower cost MRIs with machine and AI read scans.

Discussion comment:

I am saddened beyond belief that men like me with a family history of prostate cancer won't have an automatic screening from 50 if the review's conclusions are adopted. That means the review seems to accept that 1 in 4 of men like me, and there are thousands of us in the UK with fathers with prostate cancer, will die unless we take very assertive action ourselves. And I am saddened to the point of disbelief to think that we know that black men are twice as likely to get prostate cancer, but that even these men, with an easily identifiable and visible characteristic won't be prioritised for screening. Put in another way, NSC is accepting that its OK that twice as many black men will die of prostate cancer under their conclusions. Is this not in contravention of

	equality legislation? I can't think of another area of risk where we just accept that twice as many people from one racial community will die because the provision specifically denies equity. Recommendation comment: Screening should be recommended. The human cost of late diagnosis and early death from a cancer that grows in a contained and treatable way is simply not acceptable. The NHS cost of treating late-diagnosed prostate cancer is astronomical and I have lived the human misery which is intense and degrading. So there is no financial argument, it's a matter of spending the money earlier in men's prostate cancer journeys. Alternatives comment: At the very, very least, intense and regular media campaigns to raise awareness and a change in primary care policy so that GPs grant PSA tests to all men who ask for them. MANY MANY more men will die from prostate cancer than died from AIDS in the later part of the twentieth century when MILLIONS was spent on awareness, why not do this for prostate cancer? Awareness campaigns should focus on black communities. Men with family histories of prostate cancer should be on a database so that GPs are aware of family history. Working with prostate cancer charities, NHS could revolutionise the diagnostic path which is complicated because it contains choices. All the prostate cancer charities have schemes to help men make good choices to prevent the harm of overtreatment to the recently diagnosed, and this is essentially free to the NHS and the men themselves, so there is no financial excuse not to do this. Other comments: Look to other countries who are ahead of us. Some of them very small countries, and follow their lead and arguments which are capping prostate cancer deaths.
P706	Affected Comment: My brother in law has recently been diagnosed with the disease, like his father before him who died of it. Several of my friends have also succumbed to it in the last few years. I have two daughters, and both their fathers in law have been diagnosed with prostate cancer. Discussion comment: Many men alive today, having been diagnosed and treated for prostate cancer, would otherwise have died had it not been for a PSA test. It's not perfect but it saves lives. The overtreated men with which you seem disproportionately preoccupied, may well have died had it not been for treatment at all, thanks to a PSA test. Recommendation comment: Screening should commence without delay.

	Current options can dramatically minimise overtreatment, which is inherently better than dying.
P707	Affected Comment: My ***** was a health conscious and very active individual, who exercised, ate healthily, did not smoke and maintained a sensible BMI. In ***** he started to get ***** and sought medical attention from the local doctor, who advised a *****. Over ***** , his symptoms worsened and despite seeking further medical advice, the doctor was adamant that the initial diagnosis was correct. His suffering increased until he became largely bed-bound with the pain, at which an ambulance was called. The hospital conducted a blood test and the results showed a very high level of PSA. Subsequent scans revealed prostate cancer, which had metastasized to his bones, primarily, his spine. From this time, I witnessed his decline and subsequent struggle for life, and the awful pain that he endured toward the end. He succumbed in ***** and his suffering haunts me every day of my life, it has left me with a mental scar. I am frustrated and angry that the doctor seemed ignorant that his symptoms presented were illustrative of potential prostate cancer, instead, leaving him ***** of suffering, having been told to “exercise the pain away”, whilst, in real terms, the cancer was continuing to develop in his body, I ask myself if a quicker diagnosis may have detected the cancer before it metastasized and, importantly, I question that if there had been an approved testing programme for PSA level monitoring, my ***** condition would likely have been detected and diagnosed earlier, potentially changing the whole story for my beloved *****. What this has left me with as well as the mental scars from my ***** suffering, is a significantly raised awareness of the potential for prostate cancer as one gets older, and the absolute importance of regular PSA analysis. Monthly contributions to Prostate Cancer Research and the information that is provided to me reveals that prostate cancer is the biggest cancer killer in men. Based upon this, I am astounded, that despite advances in testing practice, there is no national screening and for me, despite the death of my Father, I have to actively request a PSA test from my GP, I am not automatically flagged as being at a higher risk. Evidence Comment:

Prostate cancer is the biggest cancer killer in men; research is being carried out by professional organisations, including Prostate Cancer Research, who have presented an academically and medially robust recommendation to the UK NSC.

I understand that one of the comments made by UK NSC for refusal of the proposed implementation of a screening programme was a claim that it would cause over diagnosis, over treatment and even treatment which is not necessary. As an *****, I am very aware of the importance of the robustness of data and the effect that measurement uncertainty brings to confidence in the respective data set. However, Prostate Cancer Research, through their various research programmes have proposed what I believe is a very well-considered and thus robust monitoring programme that will provide robust data with an acceptable level of uncertainty, therefore, providing data that can be statistically analysed and implemented back into the programme in a closed loop regime to provide a system of continuous improvement.

I can say from personal experience, that late diagnosis, caused significant suffering and ultimately the death of my *****. To reject the screening proposal appears to be ill considered and appears to illustrate a lack of awareness of the severity of the problem and a lack of understanding of the screening proposal.

Discussion comment:

I felt confident that UK NSC would embrace the proposed screening programme; as I commented in my response to question 2, it appears that there is a reluctance for change and development within the system, primarily due to measurement uncertainty. Measurement uncertainty is reduced by carrying out a measurement system analysis (MSA), to identify and analyse input parameters and thus the level of confidence that each bring to the system and to therefore statistically focus on improvement methodologies for the lower confidence factors.

Therefore, I feel that UK NSC need to reconsider the proposal and allocate expertise to conduct further analysis in order, through a thorough MSA, to make a concerted effort to allow a screening programme to be implemented and continually developed, rather than simply rejecting proposals that have been professionally conducted which illustrate viability.

Recommendation comment:

A screening programme should absolutely be recommended, in the first instance, for individuals and groups who are at the highest risk, for example, individuals who have had a close family member suffer from the condition or ethnic groups who have been shown, statistically, to be prone to the condition. To clarify, once again, a professionally conducted MSA, as discussed in Question 3, will provide appropriate statistical data for the target patients. Prostate cancer is the biggest cancer killer in men and therefore, how can it be a fair and robust decision to reject a proposal that presents a viable methodology for the provision of a screening programme, in the first instance, to a targeted audience.

Alternatives comment:

We need an increased awareness of the severity of this problem. Most of us are aware of breast cancer and how serious that is in women, but in comparison, prostate cancer is relatively unknown by the general public, including myself, until my ***** was diagnosed with it. I would go as far to say, that ignorance of the condition, it's prevalence and symptoms, is equally prolific within the medically qualified community; this is based on my experience of complete and total misdiagnosis of my ***** condition by a GP, and my subsequent experience of, despite his death, still having to request an annual PSA test from my GP, with nothing on my file highlighting the fact that I am at higher risk because of both my age and family history of the disease; to me,

	this is both offensive and totally unacceptable. It should be relatively straightforward to educate the relevant medical practitioners. The Prostate Cancer Research organisation are doing sterling work to increase awareness of the prevalence and seriousness of the disease to the general public, through television, media and their website. In comparison, the availability of such information is very sadly lacking within the NHS system, this should be addressed. A well-considered and delivered regime of education will highlight those at risk and reassure those who are not and thus provide specific individuals who can be targeted to be advised to seek medical opinion. Other comments: Medical technology is subject to constant development and advancement; research into causes, prevention, screening and treatment of prostate cancer continues apace. As prostate cancer poses such a significant threat to older and particular ethnic groups of males, screening programmes should be under constant review as fresh evidence emerges from research and development studies, from patient data and from relatives affected by loved ones suffering from the disease. Incorporation of AI in order to assist in the collation and analysis of data on an ongoing basis, will create a powerful system that will inform from both medical and personal human experience and thus guide the implementation of an appropriate, viable and constantly developing and improving screening programme that is not human labour-intensive. Development of this AI based system should be proposed to chosen universities and offered to students on medical and computing courses; I would suggest as a Masters study level group project, which would facilitate the incorporation of students' on respective medical and computing study programmes to work together as a team to research and collate appropriate academically robust data from all appropriate sources, including individuals suffering from the condition and those deemed to be at higher risk of developing the disease. The student team then bring this all together in the development of their proposed system to provide a solution. The project should be duplicated and presented to a variety of chosen university institutions in order to develop comparative systems for review and analysis and final development of the most powerful and capable system. The primary customers for this project should be chosen members of UK NSC and Prostate Cancer Research, which will nurture relations between the respective organisations. These customers would work with the respective university academic supervisors and student groups.
P708	Affected Comment: I had a routine blood test as part of a treatment for ***** and because of the campaign and the publicity around it, I asked for a PSA test to be done at the same time The results came back through the NHS app, I had a PSA of ***** As you can imagine it was a shock and I am *****. It is my fault as ***** a urologist recommended periodic PSA tests, but I did not make the effort to have them done. If PSA testing was routine and instigated by the NHS, some action might have been taken before it got this high. Recommendation comment:

	It should be recommended to pick up treatable prostate cancer early. I don't want other men to be in my situation, where I suddenly out of the blue have a greater than 50% chance of having cancer.
P709	Affected Comment: I was diagnosed with stage 1 intermediate Prostate Cancer *****, and I had ***** of hormone therapy and then ***** rounds of radiotherapy at ***** in *****. I was lucky that I was diagnosed by my GP as although I went to see him about another matter I commented on having to get up during the night to pee! So I had a physical check on the spot!! My concerns are that it was a fluke that I was diagnosed. There needs to be a proper screening process for all of the UK rather than relying on luck Recommendation comment: As above there cannot be enough information given out about this Screening will prevent a lot of unnecessary deaths in men Alternatives comment: More understanding of this cancer for men Take it to the workplace and get Prostate Cancer survivors to talk about it and offer their support and understanding Better role out of new testing and procedures
P710	Affected Comment: Hi my husband of ***** years died of prostate cancer in ***** after a ***** year fight. I strongly believe not enough money is being spent on finding better medication to fight this disease Recommendation comment: I totally think screening should be introduced from the age of 40. Too many men are diagnosed at stage 4 when this could be caught much earlier. Alternatives comment: Screening is the only effective way as most men have very few symptoms

P711

Affected Comment:

I have recently been diagnosed with Prostate Cancer.

I attended a prostate cancer roadshow in ***** in ***** at which a blood sample was taken. This revealed a high PSA level of ***** and I was advised to visit my GP. I had a further blood test at my GP surgery in ***** which reported a PSA level of *****. I then had a prostate scan and prostate biopsy in***** before being informed that I had an enlarged prostate and prostate cancer by a urologist at *****. I am *****. I have also started a course of hormone therapy.

My prostate cancer has been found in the early stages and the NHS appears to be doing all of the right things. However if I had not attended the ***** roadshow, I would be unaware of my condition. For this reason, I believe that regular testing of older men (over 50 or 60) is important to detect prostate cancer and start treatment at the earliest opportunity.

A PSA test does not give a 100% guarantee that prostate cancer is or is not present, but it will definitely detect prostate cancer for those who have the condition.

Evidence Comment:

From the evidence considered, the conclusions are simply wrong.

Discussion comment:

In my opinion, the conclusion to NOT introduce regular testing for prostate cancer, (similar to bowel cancer testing or breast cancer testing) is driven by a lack of NHS resources to provide testing or financial constraints upon the government.

If government cannot afford to introduce regular testing, it should make an open statement to this effect.

If NHS resources are lacking, further investment in clinicians will be required.

Recommendation comment:

The cost of introducing screening will be considerable but these can be offset by cost savings in hospital treatment, GP time, nursing care and other healthcare.

Prostate cancer creeps up on a man with no warning. Every man should be entitled to enjoy a full life and to have his medical conditions treated.

Early diagnosis of Prostate Cancer is essential to prevent early death and screening is essential.

The arguments for prostate cancer screening are similar to those for screening for bowel and breast cancers which have been very successful and extended the lives of many men and women.

Alternatives comment:

Prostate cancer mainly affects older men over 60/70. A screening programme should therefore be focused on the high risk groups.

Other comments:

	If the causes of Prostate Cancer can be reliably identified (e.g. bad diet, alcohol, smoking, weight issues, etc.), a health education programme could be designed to inform men of all ages what prostate cancer is and how best to avoid the risks of contracting it. Most young men are unaware of the location or function of the prostate and a health education programme using social media would help to improve awareness. Prostate education should also be introduced in secondary schools or at universities and colleges.
P712	Affected Comment: I was offered a PSA test by my surgery in *****. *****, so I was surprised to be given a Stage 2 diagnosis. As my ***** had died of *****. I was surprised who I felt and recalled what my ***** had gone through. No one should ever go such distress. I asked for an MRI, which detected an abnormality, followed by a biopsy. I had my prostate removed in *****. It had become locally Stage 3. Fortunately my quarterly PSA tests since then have been *****. The support that I got from the NHS and my local Prostate Cancer Support Group in particular was invaluable in helping me through this crisis. Evidence Comment: I feel that the NSC was far too cautious. In the time between my initial test and operation, my cancer had developed from Stage 2 to Stage 3. I was told that my Stage 2 cancer was not aggressive. It would appear that this was not quite the case. NSC only suggests tests for men with confirmed BRCA1 or BRCA2 gene variants every 2 years. How will they identify such people? They also do not target other men at significant risk, namely black and those with a family history. I am not black, nor does my family have a history, but I still developed a version that required intervention. Discussion comment: I do understand that prostate cancer develops in most men and that most cases will be Stage 1 and only require monitoring. More work is required to understand the full extent of the problem.

	Working with Transform is a small step in that direction, but this could have been more radical and transformative. Recommendation comment: My view is that screening should be the default option with a clear pathway supplementing the results. For example, offering an MRI if the initial PSA shows a level of concern. If that is clear, then future PSA test can be used to monitor the levels. In particular, those men at particular risk should be targeted, that is men with confirmed BRCA1 or BRCA2 gene variants, black men and those who have a family history. I would not have been detected. Alternatives comment: There is still a big worry about the Big C. It need not be a death sentence if caught in time. A public information campaign featuring those men who have been successfully treated would be of benefit. Other comments: One of my friends in my local Prostate Cancer Support Group tried to pass on some leaflets to his local surgery. These were leaflets from trusted sources, such as Cancer Support. The receptionist refused to allow them in the reception area, treating them only as circulars and only grudgingly allowed them in the vestibule. A training opportunity for support staff perhaps?
P713	Affected Comment: The condition has affected me in so far as I have an incurable prostate cancer diagnosis at ***** years old, but this has significantly affected my family and friends as well. Evidence Comment: Harms stated as being caused by overdiagnosis seem to have been exaggerated. Especially when balanced with the risk of missing the disease. This does not seem to align with respecting patient choice? Göteborg and ERSPC Studies do not seem to have been considered in relation to pro actively inviting men for a PSA test? Saving 1 life seems to be comparable to other screening programmes when considered within the parameters of targeted and not blanket screening. Emerging evidence around less grey imaging ultrasound and MRI without contrast both modalities of which could determine the need for a biopsy does not seem to have been considered. A biopsy to establish Gleason score would be needed if cancer is seen on US or MRI. I can't see any evidence in the report to consider this best practice use of imaging? Some of clinical trials the NSC has based their decisions on are older studies and do not stack up to critical appraisal. Discussion comment: The conclusion and consequent recommendation does not appear to be made based on contemporary research? Imaging including less grey imaging US and newer MRI not requiring contrast does not appear to have factored into the reasoning?

The report does not seem to balance the available evidence for a targeted screening approach including black men and those with a family history. Rather a blanket approach including those with no increased risk has been surmised on?

Although including BRCA gene group in the new study is a step in the right direction, very few people know they are BRCA positive until they are diagnosed with cancer and then seek genetic counselling. Why would people come forward for BRCA gene testing? I only had genetic testing as a consequence of my prostate cancer diagnosis because I had a family history. After the fact it helped guide my on treatment eligibility and whether my children would need genetic testing.

Recommendation comment:

Screening should be recommended with the caveat that this should be in a targeted way. Those with a family history and black men should be proactively targeted given their well evidenced increase risk of diagnosis.

By using patient medical records, Primary care should pro-actively invite these groups for a PSA +/- a newer MRI not now requiring contrast (no Doctor needed to be present- reduced costs and NHS burden) or less grey imaging specialist ultrasound. Only at this point might a biopsy be required which should be transperineal.

The consequence of not screening could be my position where the disease is caught to late meaning years of life lost, impact on family friends and me, and significant additional treatment cost to the NHS to extend life. The cost of my ***** of chemo,***** radiotherapy sessions and lifelong hormone therapy associated with all clinicians involved in my care would not be insignificant.

It would not be an understatement to state the large emotional impact the diagnosis has had on me my wife and two small boys and all who know me. Life changing. Screening could have offered a diagnosis when I could be cured.

Alternatives comment:

As a stage 4 prostate cancer survivor I'm always struck by the difference in the prostate cancer community between the incurables and the curables. As an incurable I lament the lack of a screening programme knowing it probably would have shifted me to the curable group. It's terribly hard to rationalise not offering a targeted screening programme when I and others are living the consequence of inaction around this.

I'm not asking for a blanket approach which might capture men that would likely die of another condition rather than their active surveillance low grade disease. This is about the thousands of men like me who have a family history and then ended up in an adhoc lottery of either PSA was screened as part of a Wellman check. For many of us the PSA comes when we are symptomatic and it is too late.

Please consider a targeted screening approach.

Other comments:

Realise the benefits of less grey imaging US and newer MRI without contrast into your decision making for those with a family history and black men.

I'm fully aware your decisions must be grounded in a strong evidence base. I'm less convinced you have considered all of the evidence and contemplated a screening programme within the

	rubric of a targeted not blanket screening programme. Please don't wait for the Transform trial conclusion.
P714	Affected Comment: I have an enlarged prostate, which fortunately was diagnosed through BUPA, this meant that there were no delays for me. However, ***** were diagnosed with cancer, which took time to diagnose, but once this had happened, treatment was quick. I worry every year about the prospect of being diagnosed with cancer. I believe we should be proactively testing for prostate cancer, to ease the stress and worry to individuals. Evidence Comment: Why would you not be proactive on one of the biggest killers in males. Discussion comment: I feel that uncertainty is being used as a reason for inactivity, men are known to be poor in talking about issues. The decision to not use screening is in a way confirming that there is no need to be proactive. Recommendation comment: We already have targeted screening for females, surely this should be the same for males. As a first step why not target those that are considered high risk.

	Alternatives comment: Organised prostate cancer testing for those considered to be higher risk. Better access to PSA testing, looking at my network access to this test is not the same across all GP surgeries. Make sure that public information continues to be a high priority. Other comments: Policy should remain under constant review and re-evaluate any new evidence as it emerges. Ensure that patients and communities are involved in future decisions. Whilst I except that screening decisions are complex, we must not ignore the impact these decisions have on the mental welfare of males.
P715	see attachment -- *****

UK National Screening Committee

Consultation Comments Pro-forma

Screening for prostate cancer modelling study

Name:	*****	Email address:	*****
Organisation (if appropriate):			
Role:	Retired GP		
Do you consent to your name being published on the UK NSC website alongside your response?		Yes	
Section and / or page number	Text or issue to which comments relate	Comment <i>Please use a new row for each comment and add extra rows as required.</i>	
	Family History	Both my elder brother and myself have been diagnosed with prostate cancer	
	Should a screening program be initiated.	I appreciate how difficult a decision this is because a) the PSA test is so unreliable and b) if malignancy is detected there appears to be no reliable method of predicting how actively the malignancy may behave. Treatment is associated with side effects that may cause serious impairment of quality of life. Therefore overtreatment can have serious adverse consequences. I think consideration should be given to screening of those with wider known risk factors than recently advocated. I think research into determining how invasively an individual tumour may behave is urgently required to help decide how it should be treated.	

Please return your completed form to the UK NSC Inbox UKNSC@dhsc.gov.uk by 11.59pm GMT on 20 February 2026.

P716	Affected Comment: Yes, it affected us all significantly Evidence Comment: Clearly the evidence considered by the review was lacking in a number of key points. Discussion comment: The conclusions are flawed Recommendation comment: Screening should be strongly recommended. Many people are dying as a result of no screening! Clearly the review committee have not experienced this in their own family, otherwise the outcome would have been different! Alternatives comment: Screening is the way forward
P717	Affected Comment: I am an active ***** year old man who was diagnosed with T3B Prostate Cancer only after having a private health 'MOT' through *****. I had no symptoms whatsoever Recommendation comment: IT MUST be. I am so lucky – if I had not had my PC picked up during a PRIVATE health check I would not have been diagnosed until it was too late. Yes the anxiety and physical discomfort caused as part of the diagnosis was not nice, BUT I would have had no problems with that if it turned out the condition was not there after all. Alternatives comment: Encourage men to have a voluntary screening via the NHS Other comments: Are you a man over 50. Get tested!
P718	Affected Comment: Yes, I was diagnosed with Prostate Cancer following a PSA Test Recommendation comment: I think that routine PSA testing may help many individuals be diagnosed at an early enough stage to save long drawn out treatments aimed at survival when early diagnosis may enable surgery to prevent any metastases.

P719	Affected Comment: Since being diagnosed last year. It's been very stressful for myself and my wife and daughters, not knowing how this disease is going to effect me in the future. Recommendation comment: Screening should 100% be carried out on all men who are considered a risk. I took the test last year because it was offered at my local Pharmacy for free for a week. My wife asked me why I was getting it done as I didn't have any symptoms then and still don't. It's just as well I got tested as my PSA was high and a subsequent MRI and biopsy proved positive for prostate cancer. Alternatives comment: I don't believe at the moment there is no alternative test to diagnose protate cancer. Testing PSA of men is priority
P720	Affected Comment: Yes, In *****, *****, I was ***** and whilst being examined for *****, was found to have a high PSA Of *****. Scans and biopsies showed that I had an aggressive cancer. I was ***** to have an extraction, and instead was treated with hormone therapy and extensive radio therapy. My PSA was reduced to *****, but I am suffering the side effects, the main one being brittle bones, which have fractured. I am finding it hard to get over the trauma. Whilst being a *****, I wasn't aware of my body. A regular screening would have avoided much of this.n/a Evidence Comment: n/a Discussion comment: The recommendations would not help others in my situation. Recommendation comment: Should be recommended. See above. Alternatives comment: More information.Screening for Women's cancer works, so men should be treated in a similar way. Other comments:

	see above.
P721	Affected Comment: I was diagnosed after *****, eventually my GP suggested they did an x-ray which showed concern's that made them do a PSA test. This came back raised and I was fast tracked for multiple scans and a biopsy. My results were Gleason 4 + 5 with high incidence of bone mets. Had I been screened regularly this could have been caught far earlier and my survival rate would be significantly higher Evidence Comment: You may not have missed anything however you've thrown me under the bus with your pathetic decision not to have a national screening programme. Discussion comment: Prostate cancer is higher in men than breast cancer in women, yet women get called for a mammogram every 3 years whilst men get forgotten about. Let's have some equality in health Recommendation comment: Yes screening is essential Other comments: How about having a male patient representative on the committee instead of a female, there would be a public outcry if a male was the patient representative on a health matter that effected women
P722	Affected Comment: I was diagnosed with advanced PC after I asked for a PSA test during a meds check.

	If an annual PSA had been done an early diagnosis could have caught it earlier allowing for easier treatment Recommendation comment: Treatment of early recognised PC is bound to be better for the patient and cheaper for the NHS Alternatives comment: What alternatives?
P723	Affected Comment: Yes – my PSA went from ***** to ***** after regular screening and hence the cancer was detected Evidence Comment: Basically we should all be screened Discussion comment: Please make screenings nationwide and encourage all to get involved Recommendation comment: Essentially gives a better chance of early detection Alternatives comment: PSA is the best Other comments: Please review the decision and save lives
P724	Affected Comment: I have been diagnosed with prostate cancer in *****. Fortunately I am a ***** and knew I was high risk with a family member with pCa and I am black. I therefore insisted I had psa test from the age of ***** to set up my baseline. There after I insured on an anual psa assessment from my GP. At age ***** my diagnosis was confirmed by MRI and biopsy. Recommendation comment: I believe screening with the best available tools will improve the outcomes of men diagnosed with P Ca

	I understand that new techniques are currently being developed to improve the accuracy of the PSA test Alternatives comment: Prevention is better than cure. Educating healthcare professionals to be aware of the high risk patients. Other comments: Improve sensitivity and accuracy of home PSA tests as a way of distribution of home testing kits, or offer a test like Faecal occult blood test kits to patients
P725	Affected Comment: Asked for a test as part of a well managed check at *****. Spur of the moment. PSA of ***** with aggressive cancer but still retained in the prostate. Had I waited until symptoms appeared, things would have been much worse. Hormone therapy and radiotherapy seem to have it under control. Dealing with cancer that is spread is far more costly and life affecting. Recommendation comment: Should be in place. Alternatives comment: Contact for all over a certain age or risk group should be a minimum
P726	Affected Comment: My husband has prostate cancer, just starting his treatment. He requested a PSA test as his father also has prostate cancer. He had the rectal exam, which there was no evidence of cancer, but the PSA test results were really high, and he was diagnosed with a medium grade large tumor in *****. The PSA tests should be available to all, just as pap smears are on offer to ALL women. Lots of men are waking around not knowing they have prostate cancer due to them not being able to have a simple blood test, probably saving the NHS millions by catching it early so not having to have much more expensive treatments, leaving families without partners, so having to rely on universal credit to help keep their family, plus all the costs of treatment due more advanced stage cancers and taking up vital resources like district nurses extra doctors visits with end of life care. Please put a national screening in place, or at least, if you ask for a PSA test, you can get one, as my husband's brother asked for one as it runs in the family, to be told they won't do it as he's not got trouble with his waterworks. My husband didn't have any trouble until around ***** he

asked for the test, but the tumor had been there for some time, just in a position it didn't effect him until it got big.

Evidence Comment:

I'm using a mobile phone and the documents are zip files, which I can't open. Maybe in future, PDF files would be better

Recommendation comment:

My husband requested a PSA test as his father also has prostate cancer. He had the rectal exam, which there was no evidence of cancer, but the PSA test results were really high, and he was diagnosed with a medium grade large tumor in *****.

Without the PSA test, he wouldn't have had a clue he had cancer

Alternatives comment:

How would they know they have the condition without the blood test?

How can you have alternatives to help people with the condition if they don't know they have it?

Other comments:

National screening for men for prostate cancer, and not in their 50's or 60's but mid 30's, so if they want to take up the offer of screening, they can, just as women have pap smears to pick up cervical cancer and had saved many lives

Affected Comment:

I have stage 4 incurable prostate cancer. I was diagnosed aged *****, *****. I do not have a BRCA gene variant. My cancer is estimated to have been present for ***** before diagnosis. My cancer was found purely by chance on a GP request for a PSA test because of my family history. My PSA level at the time was *****. I had no symptoms evident.

This could have been caught ***** previously and at an earlier and curable stage. I am quietly angry. My prognosis at diagnosis was *****.

My ***** prostate cancer was successfully removed and is now thankfully cancer free.

My ***** sadly died from the disease.

My family has suffers the emotional turmoil of my diagnosis psychologically to this day. My *****.

I have friends who are affected.

***** whose ***** died from the disease and is aware.

***** who is aware now of an increase in PSA levels and actively watching.

***** sadly passed away unaware of symptoms.

Evidence Comment:

The recommendation of screening for the BRCA gene variant would have missed my diagnosis. My family history should have been an alarm call.

I am white Caucasian, under the typical age of concern.

Ref. 4.1 evidence review document.

From my perspective regarding Whole Population Screening. "Better the devil you know" and early warning and awareness would be an obvious benefit. Friends have benefited from early PSA screening. If some of the concerns are increased psychological harm then measures should be employed to deal with this possibility.

Discussion comment:

Addressed above.

Recommendation comment:

Yes I do think screening should be recommended.

I am biased but my cancer would have been caught in time and my life going forward would be very different.

Alternatives comment:

As my diagnosis was made ***** options were then limited to upfront androgen deprivation therapy. This thankfully turned out to be a fortunate outcome as has worked perfectly.

	What I did need was professional psychological support. This was thankfully provided by a charity attached to my hospital *****. The ***** provided much needed ***** counselling *****. Through a greater understanding of other men's treatment pathways via social groups and connections, I was surprised at how this is a secondary consideration in treatment. I consider this essential in my emotional recovery and treatment. This should be considered part of a treatment plan. There is mention frequently of the psychological harms of treatment as well as diagnosis, therefore it would make sense to initiate this pathway as a recommended option. I think that it's well known that men are generally bad at dealing with emotionally testing matters. The nature of these support structures (social groups, professional councillors, charities etc) feels inaccessible and disparate at the point of need. But thankfully *****. Other hospitals do not. A national structure or framework to guide hospital trusts to offer this would be invaluable. Just joining up the dots.
P728	Affected Comment: Yes it has Recommendation comment: Screening should be recommended. It can be a life saver Alternatives comment: Not making men wait for tests or results Other comments: Treatment shouldn't be different all over the UK

P729	Affected Comment: Diagnosed ***** Treated *****. Ongoing monitoring via PSA blood tests. Evidence Comment: I believe that appointments were only scheduled because I chased up, after waiting a month beyond the mentioned next appointment. Recommendation comment: I certainly believe in screening BEFORE symptoms present. I was lucky to be detected. Alternatives comment: Promote the disease as a horrible way to die if found too late.
P730	Affected Comment: I am ***** and decided I should have a PSA test as I have friends with prostate issues and I thought I had reached the age when it might be an issue. I'd also noticed I needed to pee more in the night. The day after the blood test my GP phoned me, my PSA was *****. I was in urology ***** and after various tests and scans I was told I had cancer and it had spread to the lymph nodes. If a screening programme had been set up then this could have been found before it had spread. A screening programme seems to me to be a sensible things to have. Evidence Comment: Surely it's better to find out sooner rather than later that you may be at risk. Discussion comment: Your conclusions seem to be based on economic considerations Recommendation comment: Screening should be recommended. Men like to ignore symptoms and I'd have thought the long term cost to the NHS is greater if nothing is done Alternatives comment: I do not think it is helpful to say people in certain genetic groups should be screened. I haven't got a clue what my genetic background is nor my family history as I was adopted Other comments: Yes think about adopted people who always get written off by the health system. They may be totally unaware of their family history. Whenever I go to see a medical professional I feel I have to 'come out' as adopted. I feel cast aside and unimportant

Affected Comment:

Yes. I was diagnosed at age *****. I first requested a PSA test.. which gave a figure of *****. This triggered an mpMRI scan. This triggered a biopsy. The biopsy showed ***** samples showing *****. My diagnosis was Gleason 7 (3+4); intermediate favourable. The cancer was localised. I was offered ***** radiotherapy sessions or active surveillance. I chose active surveillance. I had *****. After ***** , the MD team and oncologist recommended taking the radiotherapy. I completed the radiotherapy *****. which will be *****. I have mild, periodic ED for which I occasionally use *****; but I am *****. In addition, I take ***** and am *****. Recently, my need to urinate has become more frequent.. together with*****. I also have ***** , a ***** , and I noticed *****. Because I have already been diagnosed with prostate cancer, these *****. All ***** proved negative for cancer.

Evidence Comment:

I can't offer any reasonable comment on the evidence. I don't know of any important evidence that was missed.

Discussion comment:

The conclusion seems reasonable to me. I didn't read any more than the lay summary.

Recommendation comment:

I have to say.. I think the conclusion that screening shouldn't be recommended seems perfectly reasonable. It's easy for me to say this.. at ***** , I am in fairly good health.. and it appears that – so far – prostate cancer isn't producing a serious threat to me. There has been some disruption to my lifestyle post-diagnosis and post-treatment.. particularly ongoing fatigue. But I obviously don't know how many people with other conditions have been affected by the drain on resources that my treatment has necessarily caused.

Alternatives comment:

I'm not sure that there is much more that can be done. It is up to individuals and various organisations to keep bringing prostate cancer to the fore in the media. It might help to have short videos of case histories.. which illustrate the kind of symptoms to look out for. A range of short videos which show a balanced response to the effects of treatment might be useful. Perhaps including brief comments from respected medical sources too? I suggest this could be commissioned by the NHS or government to avoid any hint of bias. Making short case history videos might communicate particularly effectively to 'the man in the street'.

Other comments:

See my previous comment.

P732	Affected Comment: My Husband only found out he had PC when he asked for a test. GO said he b thought prostate was ok but a blood test showed differently. Luckily the cancer was caught before it spread. Without symptoms we would be none the wiser until it would be too late. Clearly. Everyman should be screened. It's criminal not to. Evidence Comment: Clearly too many men are affected and if screen would be treated sooner. Reducing the cost to life and funds Discussion comment: Everyman saved through screening is worth taking the chance and putting minds rest for those priced to be ok. Recommendation comment: Man historically think they can't be bothered. If a screening service was introduced. It would encourage men to keep a he knob them selves. Alternatives comment: Offer the various types of treatment in all hospitals not just a selected fee. Other comments: Screen everyone over the age of 50.
P733	Affected Comment: My husbands father died from prostate cancer. When my husband was *****, due to that history he asked his GP for a PSA test – this was denied as he had no “symptoms”. ***** later, he started getting up in the night to urinate. This time the GP did the PSA test – it was only ***** above the “normal” range. He had a MRI and biopsy – Gleason 9 – aggressive prostate cancer. If he had started having PSA tests when he was 50(and with the family history) it could have been picked up earlier It has devastated our lives Evidence Comment: The voice of patients and families who have actually gone through the testing process hasn't been considered at all. Discussion comment:

	The PSA test may not be perfect but it all we have. The so called unnecessary treatments are not excessive and the worry of not knowing is a lot worse Recommendation comment: It should be recommended. It is one of the biggest male cancers and should be treated as such for all men and detection be made a priority which can only be done through screening Alternatives comment: I don't think there is an alternative. The wait and see plan condemns a large number of men to late diagnosis of cancer Other comments: Ask men what they want!
P734	Affected Comment: It's has affected me. I have no family history of prostate cancer but was diagnosed at stage 2c at age ***** only due to an alert GP who referred me for further investigation even though my highest PSA was *****. It had risen from *****. Without the tests I would probably not have been diagnosed until stage 4. Routine testing is relatively cheap and would pick up so many more cases while still easily treatable and curable. How many men have to die before testing becomes routine? Discussion comment: Yes. Test men routinely and regularly from age 50 onwards. High risk men earlier. Recommendation comment: Yes, for the reasons above. Alternatives comment: Test and understand that it is the change in PSA that is the prime indicator unless science advances other accurate indicators. Other comments: No.

P735	Affected Comment: I was diagnosed in ***** after biopsy in *****. Started hormone treatment and then Radiotherapy in *****. Evidence Comment: I don't know haven't seen it Discussion comment: Can't comment Recommendation comment: What does the screening entail. If it's just PSA test then I don't believe these are reliable from what you hear. I think I was fortunate to get diagnosed. If I hadn't had a ***** which found ***** which was why I had the biopsy I don't think I would have been diagnosed because surgeon asked before I went in for biopsy if he could take samples from my prostate. Other comments: More precise means of diagnosis as PSA testing is not 100% reliable
P736	Affected Comment: It has affected myself and ***** , we both have stage 4 metastatic prostate cancer spread into the bones. Had there been a screening programme it may have been caught before spreading too far. Evidence Comment: None Discussion comment: The idea that more men are being harmed unnecessarily is just rubbish, there are plenty of tests before you get to unnecessary harm. This is clearly about saving money, not mens lives. Recommendation comment: Screening should be recommended as mine and ***** cancer could have been found earlier. Alternatives comment: There are no symptoms until it's too late, so I really do not understand this question. Other comments: Yes, start screening men from 50 putting those who are coloured or those who have already diagnosed close relatives first.

P737	Affected Comment: The impact on me has been considerate, mentally, I had no symptoms and none of my family had had prostate cancer. It was an off the cuff remark by my GP that prompted testing. My score was *****, with a reporting level of ****. It transpires that I have a highly aggressive and fast growing cancer. The cancer has escaped my prostate reducing options. Routine testing won't help me, but will save thousands, like me, with no symptoms Evidence Comment: To be honest I can't fathom how NSC arrived at it's decision. Quite rightly women have screening common cancers, why shouldn't men? Discussion comment: As I said above I didn't understand the logic of the decision based on the evidence presented Recommendation comment: Yes. Without screening, people like me without symptoms will go undiagnosed and have reduced treatment options plus an unnecessarily shortened life. Alternatives comment: To detect cancer, in a population, especially one as common as prostate cancer, screening is the only safe option. The digital exam should be stopped as it doesn't really prove a lot and does deter men – many men have said to me the finger up the bum is a deterrent, just do an MRI Other comments: Not much except that panel should reflect on why prostate cancer is known as the silent killer
P738	Affected Comment: I have metastatic Prostate Cancer. Recommendation comment: I believe that screening should be recommended. It was only by accident that my Prostate Cancer was picked up. If screening had been in place it is probable that my Prostate Cancer

	would have been picked up earlier and I could then have been cured, rather than knowing I have an incurable Cancer. Most people would prefer to accept the small number of false positives in order to save many men from dying from this disease. There is screening in place for Breast Cancer and Cervical Cancer so why not screen men for Prostate Cancer.
P739	Affected Comment: I have been living with PCa for the past *****. Discussion comment: I feel the consideration on the harms of testing have been exaggerated. If I had been tested at age 50 I would have had a better result. Recommendation comment: Screening should be recommended to a lot more men due to their risk factors such as age, race and family history. Alternatives comment: Make sure GPs do not discourage men who ask for a PSA test at any age. This is happening a lot and reduces the good work done by charities to publicise the condition.
P740	Affected Comment: Yes, this has affected my life and also my wife and family. When diagnosed, all I thought about was I was going to die. Doesn't get worse than that., Evidence Comment: I know absolutely nothing about this review., Recommendation comment: Ye, there should absolutely be screening, my cancer was found by accident. Only for that i would have found out when it was too late. Alternatives comment: Give a man a PSA test when he asks for one. We shouldn't have to fight for it, but so many men do.
P741	Affected Comment:

	It had made a big difference to me and my family. The biggest problem is waiting for results of blood test and scans, it does create lots of tension and mental anxiety. Recommendation comment: Screening should be recommended, it is only because of my Doctor sending me for a blood test that found that I had prostate cancer.
P742	Affected Comment: My brother has prostate cancer at a young age Recommendation comment: Yes because it can detect issues early
P743	Affected Comment: Yes. My husband has been diagnosed with advanced prostate cancer with extensive bone metastases Evidence Comment: If there was a national screening programme my husband's cancer may have been picked up whilst it was still at a treatable stage. He had no prostate symptoms until the bone lesions started causing problems. Discussion comment: I cannot understand why men cannot be screened as women have mammograms and smear tests. Recommendation comment: Absolutely, and for everyone, not only the at risk groups. My husband was a fit, healthy man with no health issues. Unfortunately, we now know that prostate cancer will kill him. Although, we are hoping he will still have a few more years. Alternatives comment: Not sure Other comments: No

P744	Affected Comment: Yes myself Evidence Comment: Yes the fact that before a biopsy is done an mri is done which can be very conclusive Recommendation comment: Yes definitely I was on ***** for ***** and never had a psa test if screening had been in place it might have been a different scenario than being Tod I have aggressive prostate cancer Alternatives comment: In my case ***** for ***** should have been an immediate sign. There is no other alternative to screening how many women's lives would be lost if cervical and breast screening wasn't available same for bowel screening. Yet the biggest killer in the country is not screened. It beggars belief Other comments: Make screening available to all men over a certain age and under that age for men with any family history
P745	Affected Comment: I have just had surgery for prostate cancer, I only found out because my wife pushed and pushed my gp for a blood test. Evidence Comment: Why do women get so many tests when men are just ignored, most men don't like to mither their doctor so we leave it until it's too late Discussion comment: This screening must go ahead Recommendation comment: Screening should most certainly be recommended Alternatives comment: I am now housebound, I'm frightened of leaving the house in case I need to rush to a toilet, my condition is not even recognised by the blue badge scheme, it's absolutely ridiculous

P746	Affected Comment: I suffer from PC and had to badger my GP to get a PSA test. Luckily it was still contained just. I had it out ***** now cancer free. Evidence Comment: 12000 men a year die of PC aren't any of them worth saving? Discussion comment: 12000 men a year die of PC aren't any of them worth saving? Recommendation comment: Should be recommended. 12000 men a year die of PC aren't any of them worth saving? Alternatives comment: Screening is the best way. 12000 men a year die of PC aren't any of them worth saving? Other comments: 12000 men a year die of PC aren't any of them worth saving? Screening is best.
P747	Affected Comment: It has completely change mine and my family's life's. Evidence Comment: I had no symptoms aged *****. Recommendation comment: Yes should be recommended Alternatives comment: Do the PSA test at normal bloods.

Affected Comment:

I was diagnosed with Advanced PC in *****. I have been told it's incurable and they have given me ***** to live. I was ***** at diagnosis.

Yes of course it's affected my life because it's going to be at least ***** less than it otherwise would have been.

The treatment has made me impotent and has destroyed our sex life and remaining time together.

My diagnosis was only picked up because I decided to have a PSA test at a regular well man check. I decided to have the test as a result of some of the high profile cases I'd read about. The doctor at no time of any previous time has asked me about PC or any potential family history.

My ***** and ***** both had PC ***** and my ***** died of *****. So there was a clear family history.

Evidence Comment:

I believe that the over treatment argument is flawed.

Men who are tested and found to have PC have options. If it's at an early stage they can opt for active surveillance and be monitored, therefore there is no extra risk.

Men who do opt for surgery are made fully aware of the risks and the decision is theirs.

Men like me are given no choices because we are never asked. If I had been told about family history then I would have had tests earlier. This option was taken from me.

Discussion comment:

I don't believe that mass screening for all men is appropriate, although I do believe the government needs to take a more proactive approach to prostate cancer education.

There is a clear need to screen men with a family history, black men and Brca gene. Firstly men with a family history may fall into the brca category anyway but are not currently likely to be offered gene screening.

Secondly men with a family history and black men are NOT currently asked about family history at well man checks a perfect opportunity to pick up on potential risk.

Recommendation comment:

Screening for black men, family history and brca mutation should DEFINITELY be screened. These men are at higher risk and are currently not even asked about this potential risk at standard well man checks.

Alternatives comment:

Include a PC risk checker as part of the standard well man check. Men are often never asked about family history.

	A campaign making men aware that there is a potential higher risk of PC if you have a family history of you are black Gene mutation testing for any man identified as having a family history. Education for GPs of the risks for men with a family history. (My doctor never asked me and upon a return visit apologised to me a told me he wasn't aware family history was a problem for PC) Ideally ALL black men, family history and brca should be screened in my opinion.
P749	Affected Comment: having prostate cancer i was one of the lucky ones sadly some were to late thats why PSA testing should be made compulsory and free with no charges its a shame when money is more important than peoples lives Evidence Comment: none Discussion comment: as above in my first reply Recommendation comment: yes as i was a prostate cancer sufferer this screening should be made compulsory with no charges Alternatives comment: my making it compulsory eg like other blood tests Other comments: get the government to prioritise this testing now

P750	Affected Comment: Yes. Prostrate Cancer detected *****. It has changed my life completely! Evidence Comment: My condition was diagnosed through regularly screening plus an observant General Practitioner. Although screening can be described as a sieve the same argument could be applied to Breast Cancer screening or Cervical Cancer screening. Discussion comment: From my previous comments it will be obvious that I feel that screening is beneficial Recommendation comment: Yes. Screening should be recommended and not left until symptoms or the condition makes the situation more difficult than it needs to be. Alternatives comment: Making more men aware of it and when they attempt to get tested the GP makes it difficult for them. Treatment it as seriously as other cancers earlier would be good for men and good for families. When i was diagnosed the consultant only gave me very basic information. It's only with the experience of years of having Prostrate Cancer have i learnt about it
P751	Affected Comment: Came as a shock. First hospital was useless. I changed to surgery. I have internal scarring which hurts all the time. I can only get viridal duo or caverject. I've asked for invicorp but can't get it. Apparently it's less painful. I was frightened about my wife leaving me. Recommendation comment: Should be a screening program.

P752	Affected Comment: I was diagnosed with Prostate Cancer in ***** (Gleason 3+4, PSA *****). Post surgery, the staging *****. I was only tested because my ***** was diagnosed ***** years before me; he lives in ***** and has an annual medical as standard (he was ***** at diagnosis with no family history of PC). Our ***** , however, had ***** , so genetic testing may have assessed our consequential risk. My ***** had surgery ***** years ago and no recurrence. I have needed salvage RT and hormone therapy in *****. Evidence Comment: I feel that the risk factors considered should include family history involving breast cancer, as research has demonstrated a possible link with PC. Discussion comment: I think that the conclusions were highly focussed on financial impacts of the immediate effects of increased rates of diagnosis without considering the follow on costs of late diagnosis, requiring more invasive treatment. Recommendation comment: I feel that early screening could reduce the total cost to the NHS but have my doubts about the value of purely relying on PSA testing. Alternatives comment: Education is vital to encourage men to seek early diagnosis to enable treatment at an early stage. Far too many defer testing due to fear of the results which places more pressure on the NHS in the longer term. Other comments: No
P753	Affected Comment: Yes. I'm a warrior. RALP *****. Psa ***** Evidence Comment: Yes was told for ***** psa was raised because of my *****. When it hit ***** found out I had it after mri and biopsy. Surgeon probably had it for the *****. Recommendation comment: Yes screening should be done if men want it.

P754	Affected Comment: I took the test as a friend found out he had it. Without any symptoms, I was stage 4 terminal cancer. Shame really. Now I'm on lifetime HT and am 50% of my former self. Life is hard. Didn't need to be if I had screening. Evidence Comment: No Discussion comment: No Recommendation comment: Should be definitely. Alternatives comment: Part of an annual health test with my GP. Include it in the blood test alongside iron, cholesterol etc. Other comments: No
P755	Affected Comment: ***** aged ***** aggressive prostate no symptoms as described. ***** diagnosed via PSA test *****. Successful treatment still alive Evidence Comment: It is so important to diagnose early. Saves time and money. Discussion comment: Disagree that it is not cost effective. Minimal test costs compared to treatment. Recommendation comment: Yes. Save lives. Save costly treatment when not diagnosed early. Alternatives comment: Any test that shows positive for prostate cancer would be beneficial.

P756	Affected Comment: Me – stage 3 Advanced PC Evidence Comment: Yes – it needs to be reviewed to allow a national screening Discussion comment: Yes – to not offer it is a death sentence for some Recommendation comment: Should be – it's the first line of defence Alternatives comment: More information and de stigmatisation Other comments: Please reconsider
P757	Affected Comment: Cancer diagnosis affects the the whole family especially when you have no indication there is a problem Recommendation comment: Screening should most definitely be recommended
P758	Affected Comment: I was diagnosed ***** and the first inkling of a problem was a raised PSA due to concurrent *****. ***** resolved with ***** but PSA remained elevated. Absolutely no prostate cancer symptoms but my doctor referred me on the PC pathway. That confirmed PC. RARP surgery done in ***** and now PSA undetectable and no incontinence or ED issues. PC is treatable if caught early but is usually symptomless until spread. Men over 55 must be offered routine screening. Evidence Comment: Believe the cancer sufferers and don't let people wait for a much more serious metastatic spread diagnosis Discussion comment: Being cynical this consultation exercise may be a waste of time as politicians likely already decided against routine screening.

	Recommendation comment: Yes to all men over 55 and all with a family history (my father had PC) Alternatives comment: A basic screening test is the first stage Other comments: Don't keep allowing men to die of metastatic PC. Catch it early.
P759	Affected Comment: My father died of prostate cancer, I was diagnosed with prostate cancer in ***** Evidence Comment: As this is one of the most common cancers in men, screening should be automatic for over 50's and immediate family of anybody diagnosed with prostate cancer Discussion comment: Introduction of screening will not over treat the public. Waiting until symptoms appear will only mean more people will have to go through major surgery or radiotherapy treatment Recommendation comment: Screening should automatically be offered to any immediate family after a diagnosis of prostate cancer as they are most at risk.

Affected Comment:

Prostate cancer has affected both me and members of my family. I was diagnosed in ***** following a routine medical at my local GP surgery. During the appointment, the practice nurse decided to request a PSA test – a simple decision that ultimately proved lifesaving.

I was completely asymptomatic at the time, ***** and did not fall into any recognised high-risk categories. Had that box not been ticked, I would have continued none the wiser, and the opportunity for curative treatment might have been lost.

I underwent surgery in ***** at ***** and thankfully, I have been doing well ever since.

Evidence Comment:

Relying heavily on PSA's limitations

The main reason the committee cites against population screening is that PSA testing lacks sufficiently precise discrimination between clinically significant and harmless cancers, leading to false positives and unnecessary treatments. Critics argue this emphasis may underrate newer diagnostic pathways (e.g. PSA combined with MRI or advanced imaging) that can improve specificity and reduce harms. A combined approach is required, rather than relying solely on the PSA test.

Not fully incorporating up-to-date trial data in its public summaries

Large European trials – such as the extended follow-up from the European Randomized Study of Screening for Prostate Cancer (ERSPC), showing a real prostate cancer mortality reduction with PSA screening over decades of follow-up – are acknowledged in scientific communities, but the UK NSC's draft doesn't give these the same emphasis in its public narrative.

Emerging diagnostic technologies

There's growing research on combined MRI strategies, biomarkers incl PSA, and AI-enhanced imaging approaches which may substantially improve early detection with fewer harms than PSA alone. These emerging modalities aren't yet fully incorporated into the modelling the NSC used for its current draft.

Discussion comment:

Population vs Individual Risk

The recommendation is population-based. However: * High-risk groups (family history, Black men) continue to have higher incidence and mortality. * Some may argue that a targeted, risk-stratified pilot could be explored rather than a binary "screen vs don't screen" approach.

In the absence of a structured programme, opportunistic PSA testing continues, potentially without the quality assurance, equity safeguards, and informed consent frameworks that a national strategy could provide.

While policy must be based on population-level evidence rather than individual cases, my own diagnosis – asymptomatic at ***** following a routine PSA – illustrates the potential life-saving benefit of early detection in men who would not otherwise be tested.

Recommendation comment:

I support the introduction of a national prostate cancer screening programme, but not one based on PSA testing alone. A modern, hybrid, risk-stratified approach incorporating PSA as an initial filter, MRI triage, and active surveillance protocols could better balance early detection with minimising harm. The current opportunistic system lacks consistency and equity, and a structured programme would allow safeguards, quality assurance, and proper informed consent.

Step 1 – Risk-Stratified Invitation (Not Blanket Testing)

Rather than inviting every man at the same age, the programme could:

- 1) Begin at 50 for average risk
- 2) Begin at 45 (or earlier) for higher-risk men: * Family history * Black ethnicity * Known genetic predisposition

Risk calculators incorporating age, ethnicity, family history, and possibly risk scores could refine this further.

Step 2: PSA as a First Filter – Not a Diagnosis

PSA would still have a role – but as an initial triage test only.

Key improvements could include:

- 1) Age-adjusted PSA thresholds
- 2) PSA density (PSA relative to prostate volume)
- 3) PSA velocity over time rather than single readings
- 4) additional biomarker tests when PSA is borderline

Step 3: MRI Before Biopsy

Instead of moving straight to biopsy after an elevated PSA:

- 1) MRI would be used first.
- 2) Only men with suspicious lesions would proceed to targeted biopsy.

A hybrid national programme would also include: * Standardised informed consent materials * Clear communication about benefits and harms * National audit and outcome tracking * Equity monitoring to reduce disparities

Alternatives comment:

Improvements could include:

- National awareness campaign about the right to request a PSA test – Standardised GP decision aids – Automatic prompts in GP systems for men over 50 – Clear guidance to reduce variation between practices. On various groups, I see too many men being refused PSA tests by GP practices, often on the basis that they're asymptomatic.

	Other comments: Many men still present with advanced disease because of: - Lack of awareness – Embarrassment – Delayed GP presentation Government-backed campaigns could: - Improve knowledge of urinary symptoms – Encourage earlier GP consultation – Normalise prostate health discussions The UK has seen how national campaigns changed behaviour for breast and bowel cancer – similar energy could be applied here
P761	Affected Comment: Late diagnosis of prostate cancer has had a negative effect on my quality of life and my marriage. Evidence Comment: My GP missed a raised PSA of ***** before I was diagnosed. In hindsight, I probably had prostate issues ***** before I was diagnosed. My ***** died of prostate cancer, because ***** I had no knowledge of family history. Discussion comment: It is flawed, early detection and treatment my have “cured” me. Late diagnosis has cost the NHS 40k in direct treatment, my insurance company paid out another £30k. I am now on medication that costs the NHS £3-4k a month so potentially £350k and my quality of life is rubbish. Recommendation comment: It should be recommended, had we had a dedicated screening process I would not have slipped the the net due to the incompetence or ignorance of my GPs. Alternatives comment:

	Screening is a bit late for “people with the condition “. Getting baseline and regular PSA values and trends can help identify slow growing cancer and identity non malignant reasons for elevated PSA levels. Other comments: Many GPs have little or no knowledge of prostate cancer, perhaps an education campaign might help. I belong to a patient participation group at our GP surgery. As patients we are being let down by governments try to introduce new measures and GPs try to find ways of avoiding the implementation of the new measures.
P762	Affected Comment: I had routine blood tests in ***** and they showed a raised psa..I had no symptoms. I was diagnosed with prostate cancer in ***** and had it removed in *****. Pathology showed that even though it was removed there are positive margins and I might need further salvage treatment. I was ***** when I was diagnosed. The operation has left me with incontinence problems and erectile dysfunction which has been distressing. I think there should be national screening, my cancer was aggressive and had I waited another year it would have been incurable. Recommendation comment: Please see comments above..it should definitely be recommended Alternatives comment: There should be more information about testing and more access to different treatments, in my area I was only offered removal of hormone therapy/radio therapy. Other comments: See above
P763	Affected Comment: I was diagnosed (*****).. had surgery (*****).. and given all-clear (*****). I'm a *****.. and realise HOW LUCKY AM !!! Hard to describe emotions in this journey.. and how many people (family.. friends.. and many complete strangers) were touched by my story (locally) and reacted to my media coverage (globally). In particular I completed a ***** .. raising funds.. and scaring people with *****!! Evidence Comment: I'm not close enough to the subject myself.. but am guided by ***** who give their all to the cause for better treatment and higher profile for #PC. *****.. THANK YOU 🙏

	Discussion comment: As above Recommendation comment: As above – provided most interested parties agree.. without unduly delaying PROGRESS Alternatives comment: As above – provided most interested parties agree.. without unduly delaying PROGRESS Other comments: Keep up the good work!!!!
P764	Affected Comment: Absolutely it's affected the family – emotionally, financially and practically. As a ***** my husband's incapacity following surgery has had significant impact on ***** . His recovery is way more important of course !!! He went to GP ***** – but was dismissed “PSA tests are not reliable”. ***** he was ***** removed and was told they had noticed someone with his prostate. (he had no real symptoms other than urine flow). Only after this did the GP agree to do the PSA test. The rest is history. ***** saved his life ! Nationally screening would have picked this up earlier. Don't gamble with cancer – screen Discussion comment: National screening of “vouchers” for PSA tests – regular prompts to be tested will save lives, families and NHS funding in the long term. Recommendation comment: Absolutely – we know smear tests save lives, we know PSA tests (when done) save lives – what are we waiting for ????? Alternatives comment: That question doesn't make sense – without screening some men wouldn't know they have prostate cancer so how could NHS or government help. ????? Awareness is great but only goes so far – if GPs don't support PSA testing it's pointless. Could Pharmacists take the blood tests for screening ? There are pin prick tests now available in Waitrose and online – could vouchers be give to those who need support paying ?

P765	Affected Comment: Yes..my husband Evidence Comment: Don't know Discussion comment: Psa testing should be offeredregu Recommendation comment: Yes..screening needed. My husband had no symptoms..random request psa.. Showed cancer that had spread and inoperable.. If screened it would have been curable.. He is now going to die Alternatives comment: Genetic testing.. Targeted screeningno Other comments: No
P766	Affected Comment: I was diagnosed with metastatic prostate cancer aged ***** after seeing my GP about *****. I knew nothing of prostate cancer until reading a Prostate Cancer UK booklet. If I had known before I may have had a psa test at age 50 and if found the cancer may not have spread. I am white and have been tested and have no defective BRACA genes or a family history of prostate cancer. Cancer treatment and the fear of it returning changes lives. We need to promote screening for all men from age 50 and black men or those with a family history of prostate cancer from age 45. Evidence Comment: Tha review looked at outcomes from psa testing and potential over treatment but ignored the facts that without a comprehensive programme of screening many men will go undiagnosed and possibly die from ignorance of the condition. Discussion comment:

	Like myself there are many men diagnosed with prostate cancer who do not have defective genes or a family history or are black. I think that restricting screening to those men in the recommendations and waiting for the results of the screening trial will cost lives. Recommendation comment: General prostate cancer screening should be introduced to reduce the number of men diagnosed too late for curative treatment. Alternatives comment: I dont think there is an alternative because many men are diagnosed with no symptoms. Unless the possibility of them having prostate cancer is made known to them they may only find out when it is too late. Other comments: GPs should include a psa test in annual mens health reviews.
P767	Affected Comment: I randomly went for a PSA test for Prostate Cancer in ***** after a friend had had his Prostate Removed. I was *****. I had no symptoms whatsoever and no family history of the condition (although my father died *****). I was diagnosed with T2a Gleason 4+5 therefore aggressive prostate cancer. Fortunately I was able to have my prostate removed but if I'd left it longer it would have become incurable. Evidence Comment: There needs to be a screening programme using the PSA blood test as a guide. If PSA is raised then a non invasive MRI can take place to see if there are any abnormalities, Whilst not perfect this will inevitably save lives. Discussion comment: Just screening men with a particular Gene is not good enough. Black men and those with a family history is an absolute minimum to start screening. Recommendation comment: All men should be screened from 50 with a PSA blood test with those in high risk groups being screened from 40 or 45. Alternatives comment: Raising awareness.

	Publicity campaign and not just about symptoms because many who have symptoms find it's too late. Other comments: I realise there's a cost implication to screening but it probably saves money in the long run by not having to treat people with advanced disease.
P768	Affected Comment: Yes. I have pca Evidence Comment: Not enough pc men stories Discussion comment: Only men with pc should be involved Recommendation comment: 100% recommended Alternatives comment: Education Other comments: A review of side effects of treatment is needed and men alerted to this

P769	Affected Comment: I am currently being treated for PCa with HT and RT, despite having suffered from ***** for over *****, I had never had a PSA test. Thank goodness I have a nagging friend (her husband had PCa) and an understanding GP who tested me despite no change in symptoms! After many scans we're hoping that it hasn't spread but we're yet to be sure ! I want everyone to have access to testing and a standardisation of treatment based on RWE Recommendation comment: Screening is essential to stop men dying prematurely ! Alternatives comment: We need to be testing early and as a routine as we do for bowel cancer ! Other comments: Stop thinking about money first – spend time educating the general public ! It's no good developing treatments until we identify the men to treat !!
P770	Affected Comment: My husband asked his GP ***** for a PSA test because his brother had prostate cancer. GP said you have no symptoms so no. ***** developed prostate cancer so he asked the GP again and again was refused. In ***** my husband developed symptoms, was diagnosed and is now being treated for advanced metastatic PC with hormones and anti androgen treatments. He has been told the treatment will only likely work for *****. If it had been caught earlier surgery would have been possible. Surely if there is evidence of a genetic link he should have been offered a test. Now it is too late and we feel very let down by the GP and the NHS. Recommendation comment: I understand that the PSA can be influenced and elevated for many reasons and that is one reason why tests aren't offered. I also understand that over diagnosis is an issue as a lot of men are found to have PC when they die that didn't cause them any problems. So I really don't know what the answer is in that context. However, surely if there is a family history that should ring alarm bells and GPs shouldn't blindly follow advice not to test with no symptoms. Alternatives comment: All men should be asked at any GP appointments about their urinary health. Specifically about any changes, any frequency, urgency and how many times they have to urinate during the night. Many men just put these issues down to age. “ Men of a certain age” funny remarks. Other comments: ALL men with a family history should be tested.

P771	Affected Comment: Affected me Evidence Comment: I don't know but then I'm not sure how I would find out. Discussion comment: It seems very risk averse skewed towards protecting people from over treatment rather than saving people's lives. People simply now won't come forward for testing. A missed opportunity Recommendation comment: Screening should be recommended as it will save lives and prevent more radical treatments Alternatives comment: Keep funding research into newer less invasive treatments such as Focal. Provide more centres offering these treatments
P772	Affected Comment: I am advanced prostate cancer, chance diagnosis following blood test for ***** should have been caught earlier if there had been screening. Evidence Comment: Was there anyone on the committee that had lived experience. Discussion comment: Listen to the people who have to live with PCA which screening not just PSA but more education of men and frontline medics about the early symptoms of the disease. Recommendation comment: I would not be in the position I am if there was a National publicity program to educate men and more importantly better education of doctors so that men of any age do not have to take the initiative and brow beat doctors into getting a PSA test. Alternatives comment: Screening

	Other comments: Screening by GP's to make them more aware of the disease, too many dying
P773	Affected Comment: I'm undergoing ***** sessions of radiotherapy as my pc has spread, having been on AS for *****. Test showed a raised PSA followed by MRI scan and biopsy confirmed PC. If I hadn't had a PSA test PC would've gone undetected and I'd likely be one of the 11000 a year that PCUK state are diagnosed too late to receive curative treatment Evidence Comment: I understand the NSC review didn't look at the latest evident, the ERSPC study that followed 162k men in 8 countries over 23 years that proves PSA test saved lives during that time. Discussion comment: The review suggests that PSA double negatives, patient anxiety, and overtreatment makes the PSA test a poor option to detect PC. The review overlooks the fact that the PSA test is the only option we have and all men who that are diagnosed with PC and receive curative or life improving treatment undergo a PSA test which means the test must save lives. Choosing all cause mortality as the only outcome worth considering is folly as successful treatment is ignored. Patient anxiety and overtreatment is a matter of both public and professional education and training not a failure of the PSA test itself. Recommendation comment: Screening should be recommended as the PSA test is proven to save lives and be the only option to prevent thousands of men a year being detected too late to receive curative or life improving treatment. Alternatives comment: Education to learn about all treatment options including AS. Other comments: Education about preventing PC

P774	Affected Comment: Yes *****. *****. ***** had prostate cancer *****. Friend is also positive on active surveillance. Evidence Comment: Totally asymptomatic only picked up as ***** therefore have ***** PSA tests. All good until *****. Then sudden increase on ***** PSA test triggering further investigation, advanced prostate cancer found. Recommendation comment: Very much needed if wasn't for PSA test would be totally oblivious to having prostate cancer. Alternatives comment: Public awareness campaigns, make it clear the DRE is no longer routinely done, from talking to other men this seems to be a big thing that puts them off getting tested. Other comments: Move more quickly on making new treatments available on nhs in more locations. For instance HiFu has been available for some years but very few places offer it.

Affected Comment:

Yes, this condition has affected me personally, as I have had prostate cancer. It has had a significant impact not only on my own physical and emotional wellbeing, but also on my family and close friends.

For me, there were the obvious health challenges – hospital appointments, treatment decisions, recovery, and the uncertainty that comes with a cancer diagnosis. But beyond the physical side, it also brought emotional strain, reflection, and a shift in perspective.

For my family and friends, it understandably caused worry and concern. They've had to support me through appointments, recovery periods, and difficult conversations. At the same time, it has strengthened our relationships, deepened our appreciation for each other, and reinforced the importance of health, openness, and support networks.

Evidence Comment:

The UK NSC review is comprehensive within its own criteria and frameworks, but some experts and advocacy groups believe that evolving evidence – especially recent trial data, modern diagnostic pathways, and risk-focused testing strategies – should play a larger role in future versions of the review.

Discussion comment:

Yes, I do have comments on the discussion and conclusions within the review.

While I understand the caution behind not recommending routine population-wide screening at this stage, I feel the conclusion remains overly weighted toward the historic harms of PSA screening and does not fully reflect how much the diagnostic pathway has evolved.

The discussion appears to rely heavily on older screening models where PSA testing led directly to biopsy and, in many cases, unnecessary treatment. Today, MRI-led pathways, active surveillance, and more refined risk stratification significantly reduce the risk of overtreatment and associated harms. I believe this modern context should carry greater weight in the overall conclusion.

In addition, although the review acknowledges higher risk in certain groups – including men with a family history and Black men – the recommendation does not feel proportionate to that elevated risk. Even if population-wide screening is not supported, there is a strong case for clearer, more proactive guidance for higher-risk groups.

As someone who has had prostate cancer, I am very aware of the balance between overdiagnosis and late diagnosis. The emotional and physical impact of cancer, not only on the individual but also on their family, is significant. Early detection can make a profound difference in outcomes and peace of mind.

I would welcome stronger emphasis in the recommendation on:

- Improving informed choice and awareness
- Ensuring equitable access to testing for higher-risk groups

- Actively reviewing emerging evidence on risk-based and MRI-supported screening pathways

The current conclusion feels cautious, but there is an opportunity to move toward a more targeted and modernised approach rather than maintaining the status quo.

Recommendation comment:

Yes, I believe screening should be recommended – but in a targeted, risk-based way rather than as a blanket population-wide programme.

Prostate cancer is common, and when detected early it is often highly treatable. From personal experience, I know how important early detection can be. The impact of a prostate cancer diagnosis extends beyond the individual – it affects families emotionally, practically, and psychologically. Earlier diagnosis can reduce the risk of advanced disease and improve outcomes.

However, I also recognise the concerns around overdiagnosis and overtreatment that have historically been associated with PSA testing. That is why I do not believe the solution is simply mass screening without refinement. Instead, screening should reflect modern practice:

- MRI-led diagnostic pathways that reduce unnecessary biopsies
- Greater use of active surveillance for low-risk disease
- Clearer communication to support informed decision-making
- A targeted approach prioritising higher-risk groups, including men with a family history and Black men

The evidence shows that harms exist, but the landscape of diagnosis and treatment has evolved. A modern, risk-stratified screening programme would better balance benefits and harms than the older models often cited in the discussion.

In summary, I support screening – not as a blunt instrument, but as a smarter, more personalised approach that reflects current medical practice and gives men a fair opportunity for early detection.

Alternatives comment:

Yes, there are several meaningful alternatives to a full population-wide screening programme that the NHS and government could implement to better support people affected by prostate cancer. 1. Improve awareness and informed choice

Many men are still unaware of their risk or of the option to request a PSA test. A sustained national awareness campaign – particularly targeting higher-risk groups such as men with a family history and Black men – could empower individuals to make informed decisions about testing earlier. 2. Proactive risk-based invitations

Rather than universal screening, the NHS could introduce targeted invitations for men at higher risk. GP systems already hold data on age and family history, and this could be used to trigger conversations or reminders about PSA testing. 3. Standardise access and reduce postcode variation

Currently, access to PSA testing and MRI pathways can vary by area. Clear national guidance ensuring consistent practice across all regions would improve equity and reduce delays. 4. Invest in modern diagnostics Expanding direct access to pre-biopsy MRI and supporting the use of active surveillance for low-risk disease would reduce harms associated with overdiagnosis and overtreatment – one of the main concerns about screening. 5. Strengthen GP education and support Ensuring primary care clinicians have up-to-date training on risk factors, modern diagnostic pathways, and shared decision-making would improve patient conversations and confidence. 6. Provide better post-diagnosis support For those diagnosed, more structured psychological support, family information resources, and survivorship programmes would help address the emotional and long-term impact of the condition. 7. Continue investment in research and innovation Funding research into improved biomarkers, genetic risk scoring, and more precise imaging could help create safer and more accurate risk-based testing models in the future. As someone who has had prostate cancer, I know that beyond treatment itself, clear information, timely testing, and emotional support make a huge difference. Even without a national screening programme, there are practical steps that could significantly improve early detection, equity, and patient experience. Other comments: Yes, I have a few additional recommendations that could strengthen support for men at risk of, or living with, prostate cancer: 1. Introduce a national prostate cancer risk assessment at a set age For example, offering all men a structured risk discussion with their GP at 50 (earlier for higher-risk groups) could normalise conversations about prostate health without implementing full screening. 2. Automatic prompts in NHS systems Electronic health records could flag men with known risk factors (family history, ethnicity, genetic markers) to prompt clinicians to initiate informed discussions rather than waiting for patients to ask. 3. Workplace and community outreach programmes Many men engage more readily in familiar settings. Partnering with employers, sports clubs, and community organisations could increase awareness and reduce stigma around discussing prostate health. 4. Clearer national messaging about symptoms and testing rights There is still confusion about who can request a PSA test and what happens next. A consistent national message explaining entitlement to testing, risks, benefits, and next steps would empower men to act earlier. 5. Reduce diagnostic waiting times Ensuring timely access to MRI and specialist review would reduce anxiety and prevent delays in treatment where cancer is present. 6. Strengthen survivorship and family support pathways Prostate cancer can have long-term physical and psychological effects. Structured follow-up support – including continence, sexual health, menopause support for partners, and mental wellbeing – should be routinely offered. 7. Commit to a scheduled re-review of screening evidence

	As diagnostics evolve, there should be a clear commitment to reviewing the evidence at regular intervals so policy keeps pace with medical advancements. From lived experience, the greatest gaps are often not just in treatment, but in awareness, access, and support. Even without a population-wide screening programme, there are realistic and practical steps that could significantly improve outcomes and reduce avoidable harm.
P776	Affected Comment: Husband diagnosed with stage 4 with absolutely no symptoms. Had to retire early to cope with the treatment and to spend more time with family. Discussion comment: To ignore the benefits of screening appears to consign men to the inevitability of dying early from a cancer that is curable if found early. Recommendation comment: Obviously, yes. Why would you not screen for a saved life? Alternatives comment: Give all men the right to demand regular a screening test Other comments: Get people who have been affected by this cancer (men and families of) into the discussion to see what it's really like to have it.

P777	Affected Comment: Yes me Discussion comment: Need screening Recommendation comment: Needed just like breastfeeding and bowel screening
P778	Affected Comment: Yes – late diagnosis (following Gp refusal to sanction PSA test for *****) resulted in ****. I may still be alive thankfully but the side effects of ED has had v adverse affect on my libido, confidence and greatly hampers ****. If I'd been diagnosed earlier, I may have had the options of several treatments of Hifu etc over a decade perhaps, even if that still resulted in Ralp, RT and HT later – that would have massively improved the quality of my life for a decade. Evidence Comment: Very little evidence to qualitatively assess the quality of life thereafter and during treatments. Discussion comment: I think too much emphasis is placed solely on lifespan statistics and not enough on the quality of any prolonged lifespan. Recommendation comment: Yes, to give men the chance if earlier focal treatments. Alternatives comment: Educate the GPs and make it mandatory that they cannot refuse a PSA test request. Rollout low cost MRI screening.

P779

Affected Comment:

Following a raised result from a PSA test, I was recently diagnosed with prostate cancer and had surgery to remove my prostate. I had no symptoms of having the condition, so it would not have been identified without the PSA test, and the cancer would probably have become terminal by the time that symptoms appeared.

Discussion comment:

It seems that the main justification for not saving lives by extending screening was the concern that patients could be over-treated. This is a poor justification and muddled thinking, because the best way to address the concern about over-treatment is to take actions to reduce over-treatment.

Recommendation comment:

Screening is currently the only available means of identifying possible prostate cancer in patients who have no symptoms, so it should be recommended. Without early identification through regular screening and suitable treatment, prostate cancer can become terminal.

Alternatives comment:

If there are any alternative methods than regular screening to identify prostate cancer in patients who have no symptoms, I am not aware of them.

Affected Comment:

As a wife of a man who was unable to get a PSA test via their own GP due to the Government Guidelines at the time of requesting the test and with no symptoms at the time of request. Thank heavens for a charity(a life saver) in our area that was providing PSA tests at an open day (bookable)

Although my husband was reluctant I pushed it. He'd never had a test previously.

Come on I said women have regular Breast screening / cervical tests as a matter of course!

He was found via the PSA test to have a high reading aged only ***** and then the cancer. Removal of the prostate *****. No family history we were aware of either whatsoever!!

Imagine following from this his identical twin brother needed a PSA test via his doctor couldn't get it, seriously despite stating his brother had the disease 😞 😞?!

His brother pushed and pushed and thankfully despite living in ***** , we used the knowledge of the surgeon in ***** where my husband was treated who said a MRI was required. His brother had a PSA lower reading but for the fact it was increased on the 2nd blood test via the GP and still a low reading but required further investigation as the 2nd one was found to be slightly higher.

Thank heavens this happened as he also had Prostate cancer ! Subsequently he had his Prostate removed as well. You couldn't write this could you as the saying goes ?!

So you have 2 tax payers here who are young and they couldn't get a PSA test at their doctors in different areas of the country. This is beyond belief yet it is the biggest cancer killer in the UK !! 😞 😞.

My husband's cancer had come out of the prostate "Capsule " and was just about to metastasise

Whatever happens at your meeting next a roll out of a simple blood test offered at a 50 year check up at the GP's is a no brainer is it not ?!

Evidence Comment:

please please bring in routine PSA ASAP to at least the 50 year age group of men. It would need to be explained they will need the simple yearly checks to look for possible changes in their readings to spot a difference.

Simple charts are available via the charity my husband used but a brief pamphlet would be very beneficial to men and even GP's to explain what you require to understand what really isn't "rocket Science " to "Jo Public "

I really hope you realise that both my husband and brother in law could have died of this horrific disease and they both *****.

I am incensed that they were "saved " by a charity and myself and let down by an antiquated health system !!

Discussion comment:

please read my comments above and I cannot stress enough that we cannot wait for the screening program while lives are lost meanwhile but we have to implement the PSA simple blood tests ASAP !!

Recommendation comment:

see above comments !

Act now and save lives. These people are tax payers you are letting down who fund the NHS for heavens sake

A wife of almost *****!!

Say no more but I think you understand my point now. Get the test out there whatever you have meanwhile and at least give the man on the street a choice ?!

Alternatives comment:

see my above comments.

If I could understand a PSA test then educate the GP's for starters and offer the PSA test at least to the 50 year old men although aged 45 would be amazing in all honesty.

A simple leaflet alongside the blood test would be great to explain moving on from the result.

Other comments:

see above.

Affected Comment:

Prostate Cancer Journey and the Importance of PSA Screening

****, I was diagnosed with prostate cancer. Thanks to early detection and prompt medical care, I am now in remission and cancer free, according to my consultant.

My diagnosis was triggered by an annual medical check that included a PSA test. At the time, I had no symptoms, so I would not have suspected any issue. Had the PSA test not been included, it is likely that the cancer would have gone undetected for several years, potentially leading to more serious complications.

Following surgery, my recovery involved careful attention to both physical and mental health. I have been rebuilding strength through daily walking (10,000–15,000 steps) and gym-based weight training, while following a structured diet plan to support overall wellbeing and maintain healthy weight.

This experience has reinforced the value of regular PSA screening, even in the absence of symptoms. Early detection can make a significant difference in outcomes, and including PSA in routine checks can prevent delays in diagnosis that may otherwise result in serious health consequences.

Evidence Comment:

As above

Discussion comment:

Yes. I strongly support the discussion, conclusion, and recommendation in the review. My personal experience reinforces the key points highlighted – specifically, that PSA screening can detect prostate cancer even in the absence of symptoms and enable earlier, potentially life-saving intervention. Had routine PSA testing not been included in my annual check, my cancer may have gone undetected for years, possibly resulting in a far more serious outcome. This aligns directly with the review's emphasis on the value of early detection and regular monitoring.

Recommendation comment:

I believe PSA screening should be recommended. My own experience shows that routine PSA testing can detect prostate cancer before symptoms appear, allowing for earlier diagnosis and treatment. Without the test during my annual check, my cancer could have gone unnoticed for years, potentially leading to more serious health consequences. Early detection through screening can save lives and reduce the need for more aggressive treatment later.

Alternatives comment:

In addition to a formal screening programme, the NHS and government could help people with prostate cancer by:

1. Raising public awareness about the importance of regular health checks and PSA testing, even when no symptoms are present.
2. Providing clear guidance on risk factors, early warning signs, and when to seek medical advice.
3. Ensuring access to rapid diagnostic services for men with elevated PSA or other concerns, so early intervention is possible.
4. Supporting lifestyle and

	follow-up programmes post-diagnosis, including guidance on diet, exercise, and mental wellbeing, to improve long-term outcomes. These measures, alongside a screening programme, would increase early detection and improve survival rates while empowering men to take proactive steps in managing their health. Other comments: Yes. In addition to screening, I would recommend: 1. Routine inclusion of PSA tests in annual health checks for men over a certain age or with risk factors, even if they have no symptoms. 2. Improved education and awareness campaigns about prostate cancer, risk factors, and the importance of early detection. 3. Access to follow-up support and lifestyle guidance for men diagnosed with prostate cancer, including exercise, diet, and mental wellbeing programs. 4. Research into risk-based approaches to target those at highest risk more effectively, ensuring resources are used efficiently while maximizing early detection. ❖
P782	Affected Comment: I have Prostate Cancer which unfortunately was detected at a late stage, too late for removal, or to stop it spreading to Lymph glands or bones. I have ***** had breast cancer. The ***** was screened and found to be a carrier of *****. ***** , and my ***** were tested. My ***** was clear so the anomaly must have come from my deceased *****. Apart from my *****tested positive and two *****. Sorry if I have used the wrong words but trust you understand what I have written. As far as I am aware no testing took place for BRAC1 or 2. At least it wasn't mentioned. I had no symptoms just a back pain. My GP diagnosed a muscle strain and advised me to self refer to Physiotherapy. The pain worsened I took myself to A&E although I felt guilty doing so. I was examined and given advice on stronger pain killers. They made no difference. Finally I phoned 111 on a ***** , they arranged for me to visit ***** GP who, after a DRE suspected Prostate problems and arranged for my own GP to be tested. Recommendation comment: I am aware that the current test isn't totally reliable but putting the cost of an MRI to one side too many lives are being lost.

	I know there are risks with surgery but if best practice was adopted across all NHS trusts the situation would improve. This is a medical issue not one for bean counters. Alternatives comment: There is a need to educate medical practitioners to think Prostate. Only on my third attempt to get help was Prostate considered as a possible cause. The cost of a PSA test is minimal compared with the cost of treating those of us who are diagnosed at a late stage.
P783	Affected Comment: I was diagnosed with prostate cancer in ***** and had a prostatectomy, after a year it returned and I had to have Radiotherapy and Hormone treatment and am still subject to surveillance form Oncology at my local hospital. Evidence Comment: I think late diagnosis is a problem and the results of a late diagnosis require greater weight Discussion comment: I would probably had a different outcome if I hadn't been in a relationship with a ***** who insisted I got checked had I not have been and with the lack of screening it could have been terminal. I think this personal experience and the rising number of cases for the most commonly diagnosed cancer and the worse outcomes for late diagnosis mean screening is essential. Recommendation comment: Yes it should without doubt please see comments in previous question. Alternatives comment: Helping people with the condition requires diagnosis, the earlier the better is the advice always given, early diagnosis requires screening. It is the most common cancer in men, screening is a no brainer!
P784	Affected Comment: Yes I have personally been affected twice by prostrate cancer as have my two brothers and it was a cause of death with my father. My concerns are now for my two grandsons. Evidence Comment:

	Yes, as there is strong evidence to support this is a hereditary condition, screening should be introduced. Recommendation comment: As stated previous. Absolutely it should recommended. Alternatives comment: Screening should be implemented first and foremost.
P785	Affected Comment: I am a prostate cancer survivor. Discussion comment: I feel that the recommendation is completely wrong, my own cancer was detected “accidentally” when I got blood tests for something unrelated. As a direct result, my cancer was detected very early, before it had grown or spread from the prostate, so was completely curable. If I had not had had that blood test, I would still have cancer, considerably more advanced than when it was treated. Recommendation comment: As above, I’m a supporter of screening. The PSA test is of course not 100% accurate, but it’s a starting point for further investigation – much like many other screening methods (bowel cancer etc). I had PSA test, and DRA. Neither were conclusive, but both triggered further investigation. The MRI scan – quick and non-invasive – again was not a conclusive test, but triggered a biopsy. The specialist told me at that stage, pre-biopsy, that the probability of cancer was high. Screening should be routine – “false positives” would mostly be picked up further down the line by MRI, before biopsy. Alternatives comment: Screening is effective. A second best would be a huge awareness programme, telling people to ask GP for a PSA test. Which is “screening” in everything but name. Other comments: If I had not had a PSA test, as part of another process, I would still have cancer. My father also had prostate cancer, successfully treated about *****. He was screened for ***** following that treatment, then the screening stopped. His cancer returned after ***** , and is now too advanced for meaningful treatment.

Affected Comment:

Hello, I am a prostate cancer patient. I was diagnosed with 'mild prostate cancer' in ***** and have been on active surveillance by the ***** since. This involves regular tests by the NHS. However, my 'prostate cancer journey' actually started with a private PSA test offered by my employer earlier that year (although as mentioned, the NHS did 'pick up the baton').

As an aside, I had a (normal) PSA test a few years earlier, when I was in my *****. As I recall, this was inspired by a poster campaign following the passing of a well known TV comedian and reinforced by a well known TV presenter/chat show host. After discussing this socially with a friend (who, as it happens, works for the NHS), I was encouraged to go to my GP Surgery for that PSA test.

Prostate cancer has affected me in that I consider that I'm living with a condition that could get worse at anytime. While the regular monitoring is a great comfort, I tend only to make firm plans for the short term (i.e. between the NHS tests). My family and friends have always asked how my condition is, so obviously it affects them. There is a local prostate cancer support group in ***** , whose members have provided invaluable advice and friendship.

Evidence Comment:

I have no comments.

Discussion comment:

I have no comments.

Recommendation comment:

Yes, I think that it would be great to have a national screening programme for all men at or above a certain age, starting with the 'High Risk' groups. Obviously, this will require increased resources for testing, investigation and treatment. However, I think early/earlier detection would either save lives and/or decrease the need for more radical forms of surgery (which potentially can have temporary or permanent consequences).

I recall one person who said that he had no symptoms, even though his malignancy was well advanced. I recall others saying that it was only picked up when it give them back pain, hip pain or severe fluid retention.

Alternatives comment:

I cannot think of any alternatives to a screening programme.

Other comments:

I think 'prevention is better than a cure'. I appreciate that there are several factors that can affect a PSA test result. However, there may be ways to mitigate falsely high PSA readings. For example, before the PSA tests, people could be advised not do certain things in a defined period before the PSA test or arrange it accordingly. I understand that colds etc. can affect the PSA result as well. Therefore, it may also be useful if any recent infections are documented, so this can be taken into account when analysing the result.

P787	Affected Comment: Yes, I had prostate cancer in *****. My wife thought a PSA might be useful because of my frequent toilet visits. My GP arranged a hospital visit immediately when he saw a PSA of *****. Luckily the cancer had not spread to my bones. ***** radiotherapy was delivered over ***** together with hormone therapy over *****. The cancer has not returned. A friend's husband was not so lucky. Evidence Comment: Abiraterone may turn out to be something I've missed. Does NICE hang its head in shame? Why the reluctance to help people? Discussion comment: Surely with current machinery, screening is unlikely to overkill! Recommendation comment: Obviously it should be recommended
P788	Affected Comment: I had prostate cancer in ***** and only had a PSA of ***** which was looked at by my doctor and consultant who did not think that it was significant but further test confirmed that I did indeed have cancer. The investigation only started due to a throwaway comment to my doctor about having to get up two or three times in the night to urinate. I had a successful radical prostatectomy which show that it was just beginning to spread. My ***** had confirmation of cancer shortly after together with another close friend who had screening. Both had radical prostatectomy. Another friend who had a PSA of ***** (no symptoms) has had radiotherapy. He in fact does have the BRCA1/2 gene but this was only discovered afterwards when he was screened further. Another friend was told he had to have a ***** but when they did a pre op the consultants found that it was prostate cancer which had spread to his bones. He now is terminally ill. I know of at least two other people who have prostate cancer and are on hormone therapy. Recommendation comment: I think that the recommendation to not screen is flawed and screening should be available to all. I do not understand the logic about the recommendations for the BRCA1/2 gene. How do you know that you have the BRCA1/2 gene unless all men are screened. If that is positive then you have to screen a second time for PSA. I know that research is progressing but my conclusion that screening for prostate cancer is paramount.

P789	Affected Comment: I was diagnosed with stage 4 prostate cancer after GP failed to tell me my psa was rising for ***** I was Treated for enlarged prostate for ***** & they never told me of the rise it was only by chance I attended GP surgery on another matter that I saw a junior doctor who asked what treatment I had received for my prostate cancer when asked GP surgery about it I was told junior doctors didn't know everything my dad has prostate cancer so it's in the family now extremely concerned about my son and would like him to be able to be screened annually why do you screen women for breast cancer but treat men like second best I am now left with severe lymphodema and my cancer has returned Evidence Comment: Yes the lives of men it's peanuts to do a simple psa test compared to other conditions Discussion comment: Stop being nieve about prostate cancer it ruins lives we need screening now Recommendation comment: Definitely need screening more men wouldn't have to have surgery and be able to live a life without pain & fear Alternatives comment: Treat men as they do women screen screen screen Other comments: Screen all men over the age of 40 It will save lives and money and men will be able to have early intervention and live a normal life there nothing normal after having a proscectomy
P790	Affected Comment: I am the fourth member of my family on my fathers side who has had prostate cancer. In ***** my ***** died a long and painful death from the disease. A ***** was cured of the disease in *****. I was diagnosed with prostate cancer in ***** and had a prostatectomy in ***** and now at age ***** I take PSA tests every six months to check if the cancer is still at bay. Since ***** I have been a committee member of a local Prostate Cancer Support Group. All this has brought me close to the disease so I consider myself familiar with need for national screening. Evidence Comment: I am not medical It qualified to comment.

	Discussion comment: I can only recommend that prostate cancer being the most common cancer needs a national screening programme. It is out of the question not to have a programme. Cancer of any kind is a frightening condition and apart from statistics is a painful and greivous disease which untreated is life threatning and expensive. Recommendation comment: Please see my above box. Alternatives comment: Why? Other comments: See my above responses.
P791	Affected Comment: At age ***** I went to Doctor with following symptoms – increasing need to be near toilets and waking up many times during the night. My GP initially arranged a “digit” test with confirmed a hardening of the prostrate and first PSA test of *****. This led to further “digit” test on referral followed by MRI etc. finally confirming need for treatment. The cancer was further advanced than anticipated requiring more radical treatment. Had screening be offered at say ***** , the cancer might have been caught at an early state enabling easier treatment. Since then my ***** and ***** have also been diagnosed and treated for prostate cancer. My son will now request PSA screening at age 45 as recommended due to his family history. As an aside, I have also been advised that ***** of developing prostrate cancer. Recommendation comment: Screening should be recommended. In my case, I was going to develope Prostrate Cancer, but screening would have identified it at an earlier stage. Alternatives comment: Use morer DNA profiling in NHS. Other comments:

	Increase public awareness and make screening available on demand
P792	Affected Comment: me & family Evidence Comment: No, but the report assumes that damage done currently during treatment will continue to be done. In most areas of medical treatment the interventions become better targeted and side effects less damaging. Discussion comment: the modelling doesn't seem to take account of improving procedures Recommendation comment: I was caught early by pure luck. I had no symptoms but seeing a locum replacement GP who had prostate cancer. I was advised a test at *****. I know others less lucky, only screened when symptoms were obvious and now suffering badly.
P793	Affected Comment: It has affected me for the last ***** (I had a prostatectomy ***** ago) during which time I have had to manage the various symptoms that ensued. Recommendation comment: Bearing in mind the problems men experience with the condition, I feel that the early screening programme should be continued

P794	Affected Comment: Yes I had mine removed ***** and have had subsequent problems (radiotherapy etc) I am a member of our local prostate cancer support group which holds 2 testing sessions a year. I was very disappointed to hear that there was not going to be a testing system similar to breast cancer for women. Recommendation comment: Yes I think national screening should be taking place. Alternatives comment: Encourage gps to carry out a psa test
P795	Affected Comment: Yes, I was diagnosed with an aggressive level 9 prostate cancer in the *****. At the ***** I had to push my GP hard to give me a PSA test as I had little symptoms. My wife and friends had been badgering me to get a test. To my shock and horror my PSA reading came back at *****. I then had various scans and a biopsy under general anaesthetic. I had a major lesion on my prostate but luckily it had not spread to my bones. I was put on hormones with quite a lot of side effects and then had a course ***** radiology sessions at the *****. I am pleased to say my follow up tests are currently showing my PSA reading at *****. This has been a terrible time for me and my family. Initially not knowing whether it had spread was particularly stressful. If I had not pushed for a test I could easily now be seriously ill with all the horrible treatments which go with that. Evidence Comment: My issue with the review is that it is taking a much too cautious approach. People are continuing to get seriously ill because they are being denied a PSA test or leaving things so late that their condition is caught much too late. A national screening programme, even with its current faults, would be a major way to prevent the death and serious illness of so many men. Discussion comment: I was very disappointed in the latest decision not to agree a national testing programme. I had to push hard for a test and luckily my cancer, although aggressive, was caught early and my treatment has been successful. Others have not been so lucky and many are still dying because their diagnosis has come too late. There seems to be too many excuses not to take action rather than the more positive approach of “let’s save lives even if some of the tests may be imperfect”. I am calling for a major new lobbying campaign to persuade government and the “experts” to change their minds and introduce a national testing programme for all men in a similar manner as screening for breast cancer. So many high profile people have called out for such a programme. These people need to be brought together and mobilised into a new national campaign. It is also now the time for a hard hitting message which shames the powers that be

	for not having a national testing programme. For Example: “ How many more men will die or be seriously ill before they take action” I hope you will give serious consideration to my suggestion. Recommendation comment: Definitely yes. See all the above. Because I have been through cancer treatment myself, I know so many men who, if their cancer had been caught early through a national screening programme, would now be in a much healthier state or even alive. Alternatives comment: Instead of prevaricating please just get on with a national programme. It seems there are too many excuses being put forward not to have a programme. If it's due to cost then the government need to be persuaded to fund it. Other comments: Yes, Accept that no particular test will be perfect and get on with a National Testing Programme now.
P796	Affected Comment: A friend of mine mentioned he was going for a private PSA test and as I was increasingly having to urinate during the night I went with him The result was a PSA of ***** so I immediately visited my GP who sent me for an NHS blood test which showed a level of ***** On the ***** I was seen by a locum Consultant who ordered an MRI scan with a biopsy follow up, the results of which are awaited I am a realist and put my hands totally in the hands of the professionals but I am concerned for other men who do not fully understand the need for an effective or other ways of detecting prostate cancer Evidence Comment: With a colleague who was ***** we are attempting to bring all forms of potential life saving treatments to the for front of our local Trust As a lay man in his ***** I'm more concerned for others who may be missing out and would like to take a more active part in raising awareness of treatments Discussion comment: Loudly promote SBRT

	Recommendation comment: Should be recommended Alternatives comment: Every over 50 (?) should be routinely screened Other comments: I want to bang the drum to raise the profile not only of the illness but also available treatments
P797	Affected Comment: After having the symptoms for a number of years I have currently been diagnosed with an enlarged prostate with a worsening of the associated symptoms that accompany this condition. I have been referred to a hospital consultant for further investigation, the waiting list is currently a 12 month wait. Evidence Comment: I have read the UK National Screening Committee (UK NSC) paper on screening for prostate cancer. I tend to agree with the main outcome decision not to recommend whole population screening using the PSA test as it is likely to cause more harm than good. I would ask what future recommendation there will be in regard to better diagnosis such as targeted screening and use of PSE test (epigenetic markers) including better awareness of the symptoms and possible outcomes. Discussion comment: The presentation of the facts in the paper were easy to read and assimilate. Recommendation comment: I agree with the recommendation due to the physical harm due to over diagnosis and the psychological harm such as anxiety, worry, low mood. Alternatives comment: The two main aspects which should be accelerated are: * education and awareness * use of the PSE Test – epigenetic markers blood test. Other comments: Thank you.

P798	Affected Comment: I had surgery for prostate cancer in *****. With new evidence coming to light, I'm not sure if I should have gone into a watchful waiting programme.A Evidence Comment: Am not involved enough in the specific data available to comment. Discussion comment: I think there is a case to monitor men considered most at risk by age, ethnicity, heredity factors etc That there appears to have been little or no progress in evolving a more accurate testing method than the current PSA methodology at an acceptable cost is a major concern. I understand that a MRI scanning procedure could produce more accuracy but is too expensive for a general roll out programme (over 50's). Recommendation comment: As a local charity we have funded voluntary PSA testing events for some years. Attendances are increasing, we always identify a number of attendees testing positive. In some cases a requirement to see their GP asap. So YES there should be a National screening programme for men, along the lines of the ladies breast screening program Alternatives comment: Not sure how effective the alternatives are ? Current mortality rates are too high. A national awareness programme funded by the government would be a step in the right direction. Currently well known people such as Bill Turnbull, Chris Hoy,Stephen Fry have raised awareness by their personal efforts. Other comments: How much research is underway to find a more effective test than the current PSA methodology, Perhaps A. I. could have a part to play ? Do we really understand how prostate cancer is created ?Are there any preventative measures that can be sensibly undertaken.

P799	Affected Comment: My father died of prostate cancer. I was not aware that he availed himself of any opportunities to be screened if they existed. The doctor then suggested that his sons (my brother and myself) should seek out a test every year. This has not always been easy and therefore a National screening opportunity would be very helpful. Indeed not only helpful but also essential as it might enable more men to take care of themselves if it became more commonplace. Evidence Comment: Whilst the test is not 100% reliable I understand that not only has it saved lives but also raises awareness of prostate cancer. Recommendation comment: Yes, I do for the reasons above. Alternatives comment: I am not aware of the alternatives, This suggests others might not be aware. Therefore more publicity and information would be helpful.
P800	Affected Comment: Yes, I have been affected. I was diagnosed with Prostate Cancer last year and underwent an operation to remove my prostate early *****. I am currently suffering with some post op issues but these were explained to me before the operation and it is still very early in the recovery stage so hopefully I will see some gradual improvement. Would I now change my mind and not have the prostatectomy, absolutely no way. I have just received my first post op PSA test and thankfully it is *****. Evidence Comment: I'm not sure that I can add much other than to quote my personal experiences. I had an associate, a similar age to myself, perhaps a couple of years older. He was diagnosed with Prostate Cancer and was dead within 3 months. I'm not sure if he had any prior concerns but I do know that my diagnosis was only discovered by chance. I visited the doctor because of a ***** which was starting to get me down. No other symptoms whatsoever. I was given a number of tests to check for my heart, lungs, bloods, etc. As a bit of an afterthought the Doctor said he would also do a prostate check, I'm guessing this was due to my age at the time (*****). I had no idea that the prostate could be checked via the blood and when I was called back for a second test of the PSA I had no idea this was related to the prostate. The upshot was, I am now being treated for ***** and my cancer was discovered thanks to the proactiveness of my doctor.

	I must reiterate, I had no symptoms at all to make me think I had any prostate or other related health issues. I have no idea how long I have been living with the cancer growing inside and maybe a routine screening could have picked it up earlier. Discussion comment: I have read that there were concerns that screening could lead to more negative issues than positive. Such as incompetence etc. From my own experience I cannot see how, after my blood test I underwent another three checks before surgery was discussed. MRI scan, Biopsy and bone scan. I suppose there could have been a problem with the biopsy but having the evidence of a PSA test and an MRI I would still choose to have the biopsy to confirm the diagnosis every day of the week. I cannot believe the risk from the biopsy outweighs the option of not doing screening and waiting until there is something physically wrong before visiting the Doctor. But this is just my lived experience and opinion. Recommendation comment: I think it definitely should, my reasoning should be pretty clear from my answers to the previous questions. Alternatives comment: I'm sorry but I don't know enough about other options available to the NHS. I can only reiterate what I have been through and know that all men that I speak to would not consider getting checked for Prostate Cancer before they get any symptoms by which time it may possibly be too late. Other comments: Could it be a consideration to at least target the most at risk men and run a trial alongside. I understand that the disease is more likely inherited and that the black community are also at higher risk so perhaps these groups could be targeted to form the basis of the trial. Also start the screening from a much younger age than was perceived as the norm for Prostate Cancer to strike as I believe there are increasingly more younger men being diagnosed than say 20 or 30 years ago.
P801	Affected Comment: I had a prostatectomy in *****. All of the cancer was removed and I'm now clear. Recommendation comment: Recommended I proactively sought a PSA test without having any symptoms. This action saved me as it picked up stage 1 cancer. I was *****. If I would have had the test the previous year the result would have been normal, the year after and it would have been too late. Regular screening is necessary to identify cancer on a timely basis. The oft quoted reason for not progressing

	screening is the concern that an unnecessary biopsy is distressing. It is not, unpleasant yes but no more than that and well worth it for the piece of mind
P802	Affected Comment: Not yet, but watching Evidence Comment: Where on earth can I see this review? Discussion comment: Ditto Recommendation comment: Then I wouldn't need to find a reason to see my doctor every now and then or look out for charitable screenings! Alternatives comment: Could there? You tell me what they are!
P803	Affected Comment: No Evidence Comment: No Discussion comment: No, very clear and informative. Recommendation comment: Yes, my last check was in ***** and I am now ***** and I should be tested regularly. Alternatives comment: Regular testing. Other comments: No

P804	Affected Comment: After having a routine blood test my PSA indicated ***** but my local GP thought it unnecessary to carryout any further tests. After ***** my ***** who was a ***** advised me to insist on another test by a different doctor in the practice. Another blood test and a physical examination was given to allow an MRI scan to be requested. The results showed up an anomaly. An Oncology consultant requested a biopsy. The results showed up aggressive ***** cancer cells. (***** showed *****% cancerous and the cancer had entered into my *****. If this had been regularly checked there might have been a quicker outcome for my treatment. I am unable to have surgery or radiotherapy but I am having to have hormone tablets and injections for the rest of my life!! Evidence Comment: I am not medically trained and therefore cannot comment on such matters Discussion comment: All the people at our ***** meetings all consider this could be life saving for many people who are eventually diagnosed with prostate cancer and conclude that screening would eventually alleviate many deaths Recommendation comment: I am not medically trained but would imagine if check ups were carried out on all men of a certain age one would imagine the cost to the NHS would be considerably lower Alternatives comment: What are these alternatives and would they be any better than the screening as now suggested Other comments: Yes have the screenings as suggested a save lives!!!
P805	Affected Comment: Yes. I am Stage 4 (Gleason 4+5 =9). Secondary bone cancer's includes an aggressive lesion on my ***** , which is pressurising the *****. I was diagnosed with a non malignant enlarged prostrate in around ***** with a PSA of ***** , some ***** years later I had a follow up PSA which was *****. In ***** (age *****) thinking that I had ***** , I was diagnosed with advanced prostate cancer (PSA *****) and secondary bone cancers *****. Annual PSA Checks would have identified this in its early stage. Evidence Comment: Each case is different, like my cancer, I had no symptoms that initially related to it, that is why screening is paramount. Recommendation comment:

	I think that there should be routine PSA Checks for those in the risk zone, and those over 65's.
P807	Affected Comment: As someone who has recently had an operation for an enlarged prostate (*****) following PSA testing I strongly support the motion for national screening for everyone.
P808	Affected Comment: My father suffered late in life from an enlarged prostate but died before any tests for cancer could be undertaken (he was *****) Evidence Comment: When I lived in ***** the local ***** and maybe organised regular screening for a small donation. I am now over ***** but did request a screening from my GP last year which was carried out and negative. One of my best friends aged ***** was eventually diagnosed following an illness however it was well advanced and the prognosis is not that good as it was spotted too late. Being the most common cancers for men regular screening should be undertaken for all men. Especially that there are big advances in medical treatments. Recommendation comment: Screening should be offered to all males.

P809	Affected Comment: I have been affected by Prostate Cancer. I had Radical Prostatectomy inm *****, followed by radiotherapy for ***** in early *****. I am still having ***** PSA tests (reduced *****) as PSA still shows cancer cells, but their location is not confirmed. Evidence Comment: I am not sure whether there was any data confirming - 1. how many men who hadn't had PSA tests developed prostate cancer 2. how many men had PSA tests which showed NO cancer Discussion comment: It might be useful if it might be possible to calculate how much time was lost in patients accessing treatment because they had been denied a test. It might be useful to have some idea of how much NHS money was spent on PSA tests with negative results. Recommendation comment: Definitely it should be recommended. There is some value in the argument that it is a gender discrimination as females can have both breast and vaginal cancer tests, for example, as a matter of course. It is possible that some men do not consider testing because of some of the negative views: "it's not reliable, so I won't bother". Alternatives comment: There might be a temptation to wait for community-wide testing until something more reliable comes along, so many men might be put off for the "wait till it's better" approach. Medical professionals and politicians might be braver in re-assuring the public there are more pleasant alternatives to the "finger up the bum" view! Other comments: Keep prostate cancer in public view – there are wonderful nurses, doctors, specialists, etc. to help people through a prostate journey. The same should be said of support groups like the one we have here in the *****, and like Macmillan. I feel in some areas the latter are taken for granted, which is unfortunate.
P810	Affected Comment: I was diagnosed with prostate cancer late in life, the treatment I have received has been first class, I do however believe all form of tests including PSA should be carried out to all men over

	a certain age whether considered a high risk or not, I believe in the long term this would a more cost effective option.
P811	Affected Comment: I am currently on Active Surveillance, with regular PSA tests. I have had one MRI scan and one bioposy operation. I am due my next PSA test in a few months time, and dependant upon the result, i.e. if the reading has doubled, then treatment will be decided. My initial diagnosis came "by chance", as a result of my having a CAT scan for lung problems, and the results highlighted early problems with my prostate. So, if I had not had this non-related CAT scan my Prostate cancer would still be unknown to me, as I am still NOT displaying any symptoms. Therefore provision of testing MUST be introduced widely. Evidence Comment: The evidence is what it is, but the resulting criteria for testing is dreadfully inadequate for such a serious illness. Discussion comment: The recommendation is short-sighted, ill-informed, and will miss affected patients such AS ME, potentially putting their lives at risk. Recommendation comment: DEFIN ITELY SHOULD BE RECOMMENDED. Alternatives comment: Extend the free testing programmes, as recently pioneered by ***** Healthcare Trust. Other comments: Discuss Prostate cancer at student level, to alert males to this potential disease, particularly if they have examples within their family.

P812	Affected Comment: Yes myself & my brother (prostate cancer) and family and friends knock on effects of diagnosis,surgery and treatment Evidence Comment: Seems to be cost led as the Govt. make final decision not health professionals Discussion comment: All males screened as female cervical screening Not just just higher risk men, black and familial evidence Recommendation comment: Yes screening is essential for early detection and cure which will save the NHS money in the long run Alternatives comment: Greater public awareness in a variety of locations and media outlets Other comments: No
P813	Affected Comment: I am the ***** but I write on my own behalf and do not submit these comments on behalf of the *****. As part of my responsibilities as ***** I interface with Prostate Scotland and ***** Prostate Champions (volunteers) spread all across Scotland who give public talks and raise awareness of prostate disease. During the past ***** we have had over 100 men who were asymptomatic but, after attending a talk attended their GP report to get checked only to discover that they had Prostate Cancer (Stage 2 to Stage4) Evidence Comment: I am sure the evidence that was available was systematically presented however I am concerned that there is an echo chamber effect widely across the medical community in regard to prostate disease and you are only hearing your own voices echoing back your previously held opinions. Discussion comment: The recommendation is wrong, lacks logic and is morally and ethically unsustainable Recommendation comment:

	Screening is essential from 50 years of age onwards to pick up early stages of prostate disease or prostate cancer. Early detection allows early treatment and saves costs. Alternatives comment: The PSA test whilst not without its faults and until a more reliable test comes along it is the best we have without more advance hospital tests and procedures which cost much more. Other comments: The committee's proposals are woefully inadequate but:- I agree with 1. Black, enhanced risk and BRCA1 and BRCA2 men need to have high priority but not to the exclusion of others. In Scotland the percentage supported and accessing screening on this basis would be very small 2. Age and genetics are a part of the risk to men and that many men die with Prostate Cancer and not of Prostate Cancer, however we must give men the information to allow them to make informed decisions. We must therefore screen all men initially at 50 years of age and give a basis to know if there are changes in levels of indications. I disagree with 1. The logic that all men should not be PSA tested on a systematic basis. 2. Most men do not know if prostate cancer was a primary or secondary cause of death in their family. Nor do their GPs 3. Unless specifically tested for BRCA1 and BRCA2, men, women in the general population and their GPs do not know if they are at risk. 4. The concept a screening programme for breast cancer, bowel cancer and cervical cancer has no better case in logic but they are provided across the relevant populations. 5. The sheer arrogance of the committee to claim that screening for prostate disease/cancer will potentially lead to cases of overtreatment is beyond belief and should be referred for judgement on the basis of medical ethics. The final decision about the extent of treatment must be made by the individual man on the basis of good information and guidance from his medical advisor, and based upon his individual circumstances. Bite the bullet, get on with testing and stop playing gender politics
P814	Affected Comment: Have had a prostatectomy and radio therapy followed by hormone treatment. Still able to enjoy life but sex life negated. Essential that early diagnosis is made. Discussion comment: The general public desires a screening process Recommendation comment: Must be recommended Alternatives comment: The psa s creening process would be the simplest at present Other comments: No

P815	Affected Comment: A colleague was diagnosed recently; luckily, his diagnosis was at a very early stage, which helped him get treatment and he has now fully recovered. The screening program helped tremendously, without it, it might have been too late. Evidence Comment: I am unaware of the evidence you considered, as I haven't had a chance to read it yet. Therefore, it would be inappropriate for me to comment on the matter. Discussion comment: In my opinion, screening programs should be widely available across the country. This would allow men to get tested, helping with early diagnosis. As they say, prevention is better than a cure. Recommendation comment: Screening and blood test are key for early diagnose. Alternatives comment: The PSA testing available through GP surgeries around the country. Other comments: A regular reminder like every 18 months or every 24th months.
P816	Affected Comment: I have been successfully treated for prostate cancer, and would not have known I had it, had I not been given the PSA test and subsequent biopsy. until a better test is devised, this is the best we have. Recommendation comment: It is our only chance of catching aggressive cancers before it is too late

P817	Affected Comment: I have had prostate cancer and have been treated for it, although now clear of cancer have other problems caused by the treatment. I was fitted with a catheter after second radiation treatment and was unable to get any sort of consultation in NHS so had to seek private consultation with my urologist who treated me with TURP operation. My *****died from prostate cancer as did ***** so I advised ***** to get tested. His GP was informed about his family history but refused a test as he was *****. He has since been able to get tested but has not been put on a regular programme of testing. Evidence Comment: Although high profile prostate cancer sufferers have urged men to get tested many men will ignore this and without screening may be diagnosed too late Discussion comment: Better testing techniques are in the pipeline but only Psa is available now it should be used until new tests are available. Prostate cancer is the biggest of all cancers yet not considered worthy of regular screening this can't be right. Recommendation comment: All males over 50 should be screened especially those with family history or from black community. Not all individuals have symptoms so if not tested could end up with advanced prostate cancer. Alternatives comment: Once diagnosed I would like the urology department to continue to work with the oncology department as there are many problems that occur once oncology treatment starts which could be helped by working together. Such things as urinary incontinence.
P818	Affected Comment: I had no symptoms and required treatment Tadio Therapy and Hormone treatment Post still suffering toilet issues wind problems and messy stools There are no symptoms so often Recommendation comment: Yes so important so many dying from the problem

P819	Affected Comment: I have numerous friends who have encountered prostate cancer and many of them only found out by late diagnosis as no early checks are done Evidence Comment: As a none professional I do not have the knowledge to impart on this but do feel from a public point of view earlier diagnosis would be much better than left until a late diagnosis, also could save finance for the nhs as earlier diagnosis cheaper than later surgical procedures Discussion comment: No, but think early intervention would benefit so many people from getting late diagnosis Recommendation comment: I 100%% think screening should be recommended To prevent late diagnosis and longer term complications Alternatives comment: More regular health checks with GP's and a more widespread awareness programme Other comments: Bring to the forefront to everybody the importance of having early regular health checks

Affected Comment:

My father had prostate cancer and died as a result of it when he was *****. I have incurable prostate cancer. I asked my GP for a DRE due to the family history. He DIDN'T tell me that he felt something hard when he examined me. I then received a letter to make a non urgent appointment for a PSA Test. This occurred a month later. It was only at the first Urologist appointment that I learnt that the GP had felt something hard in my prostate. I was treated with ***** in *****. My PSA remained low until ***** when it rose above *****. Scans revealed significant lymph node involvement. It is now incurable. I'm on combination hormone therapy and my PSA is currently *****. However we know that it will become HT resistant at some point.

My ***** was also diagnosed with local Prostate Cancer in ***** and treated successfully with *****.

My ***** was getting regularly tested for Prostate cancer and was also diagnosed with Advanced Prostate Cancer in *****. His GP had refused to give him a PSA test the previous year despite the family history. When he was eventually diagnosed his PSA was over ***** and it had spread to his kidneys and lymph nodes. His treatment has involved chemotherapy and radiotherapy and now, like me, he is on Hormone therapy. He knows that the cancer will become resistant to the treatment and return at some stage.

Even though as a family we've actively tried to manage getting screened for Prostate Cancer, the lack of a consistent screen programme has been to our and our families' detriment. Lives will be lost early and completely unnecessarily.

Evidence Comment:

I am commenting from a patient perspective. I understand there is concern about unnecessary invasive impact on lives, where a person might be left incontinent and/or impotent as a result of treatment that they may not have needed because they died of something else before the Prostate Cancer developed. However, I know far too many people where the diagnosis occurred too late and lives and families are being destroyed by losing a loved one unnecessarily early. If screening has to be selective then surely it must include men with a family history and ethnicities where the risks of getting the disease are higher.

Discussion comment:

The recommendation to only screen Men with the BRCA gene appears to my non-professional eye overly restrictive. Most Men don't even know they carry it. I was only tested for it once my prostate cancer had returned and they wanted to see if I'd be eligible for a new drug trial. The tests revealed that I didn't have it.

I think that the only way you might suspect that you had the BRCA gene is if there was a family history

Again, because of the above, I'd be surprised if such a restrictive screening set made much difference to early Prostate Cancer diagnosis which is surely the goal here.

Recommendation comment:

I think that Men in high risk groups should have their PSA's measured regularly from the age of 50 onwards. I appreciate that it can be a slow growing disease and one of the treatment strategies is one of watchful waiting. I understand that sometimes taking biopsies to confirm the

spread can be uncomfortable and result in infections. However, this is nothing compared to having incurable cancer and the impact of all the treatments a man has to endure and then dying early because of this dreadful disease.

Alternatives comment:

It's clear that many men have been failed by the lack of strategy across the Primary Care sector. There is a lot of evidence where the patient is better informed than the GP. A consistent policy must be developed and rolled out across the Primary Care sector. This is particularly important in poorer sections of the communities as statistics show that men in these areas have worse outcomes.

Linked to this there are many Doctors and Nurses and support staff who (I have personal experience of this) who either don't have enough information or they have the wrong information. There are central resources like Prostate Cancer UK and Prostate Cancer Research that provide a wealth of professionally reviewed information.

Also linked with this is some men's attitude to health issues e.g. putting off going to see the GP unless it's really serious. Many men with Prostate Cancer exhibit no symptoms, so even if they were in the subset of men that get embarrassed about going to the GP about potential prostate related issues, a lot of them won't even know that they have the disease. So a general education initiative for men to check for family history, awareness that it can be a symptomless diseases and to look at Prostate Cancer UK and Prostate Cancer research before visiting the GP would save many lives

The PSA test is a simple blood test. Is there a way that a simple kit could be developed like a pregnancy test or a covid test that men could perform at home? This would then allow men to test themselves without tying up NHS resources. We know that the PSA test is used as a first stage indicator and results can be unreliable in that a man can have a low PSA and still have the disease and vice versa. However, it is the best that we currently have and is still used by GPs after a DRE.

Defining groups of men that are of higher risk and therefore deserving of an earlier risk assessment for higher risk men, clearer access to PSA testing, better GP support and education, improved public information, and action to tackle inequalities in access and outcomes.

Other comments:

We need to get serious about providing a proper screening programme to identify men with Prostate Cancer early. It's accepted that there are difficulties regarding i) unreliable PSA tests ii) invasive treatments e.g. surgery that results in impotence/incontinence; side effects of chemotherapy/radiotherapy/hormone therapy, which may have been implemented too early and the man actually died of something else due to the slow progress of the non aggressive form of prostate cancer. However, both the charity funded research initiatives and the NHS have habitually risen to the challenge of finding solutions to these types of problems. I believe that with the right skill sets, wisdom and experience we can find a way to provide a screening programme that lowers the figure of 12000 men dying a year from Prostate Cancer. Some countries like the US do have a screening process.

P821	Affected Comment: I have a younger brother with prostate cancer Evidence Comment: It seems that the former concerns of over-diagnosis and unnecessary interventions with risk of side effects have been reduced by newer approaches Recommendation comment: My brother would not have found out he had cancer except a nurse suggested a blood test when some other routine tests were done. He was lucky. Prostate cancer seems to be the most common cancer in the UK now. Please start screening.
P822	Affected Comment: My Dad was diagnosed with prostate cancer at the same my Mum was diagnosed with breast cancer. Which was one was discovered by screening? Why not both? Recommendation comment: When the Breast Screening Programme was introduced it was acknowledged to be an expensive process, but felt to be justified. It was believed that but for those women who didn't attend and a fraction of miss-reported mammograms, BSP was a universal leveller for women in England. We now know that BSP is only effective in identifying cancers in women with low breast density, about 50-60% of the population. Why is this relevant? Because despite it being imperfect, despite it being costly, BSP continues because it saves lives and technologies are emerging to improve the equity of offer. So why is the NHS reluctant to take action on behalf of men? And at what point does this become discrimination on the basis of gender? We know PSA screening is imperfect. In terms of cost and value for money, PSA screening costs a fraction of the equivalent of breast screening. So financially there is no justification to deny men. A prostate screening programme will add burden to the NHS by increasing diagnostic demand, especially for MRI scans and urology appointments. But it will add value to the overall economy by saving lives. So no justification to deny men. PSA screening will give false positives and lead to further diagnostics, some invasive, only to prove unnecessary. Same as breast screening. So no justification to deny men. Prostate cancer was recently reported to be the number one of all diagnosed cancers in the NHS. What each diagnosed case represents is a patient who was able to advocate for themselves and persuade a GP to do a PSA test, or men who proactively sought a private test,

	or men who were lucky. In a modern society, in a national service that is meant to be universal, that is unacceptable. An acceptable compromise would be to introduce a targeted and informed screening programme. A modern prostate cancer screening offering could include all black men and all men with family history. Make that the starting point and expand as technology advances. Cancer of any origin has one universal truth. It cannot be treated with ignorance. Please give men a chance.
P823	Dear sirs, The question of whether to have a National Prostate Screening Programme or not will be negative on the side of logistics and costs . However my view is that whilst a screening programme will take time and the conclusion be ultimately known there will be many men who will 'fall by the way side'. In my case I had annual PSA Blood tests from *****. Cancer diagnosed in ***** , radiography in ***** preceded by MRI & CT scans that confirmed no cancer spread, and hormone Injections till *****. I am now confirmed as PSA level ***** THANK YOU VERY MUCH -- NHS. I now have PSA tests every 4 months . The point I make here is that every man 50 + should be encouraged to have annual PSA tests, that GP's should be instructed to encourage men to have the tests. The TV media should be used as a great vehicle. Those found to be in need of treatment will thus be 'pushing the system' to respond. Waiting for national screening results is NOT the response. Regards,

Affected Comment:

I was diagnosed at ***** with stage 3B PCa and was informed by my Consultant Urologist that I had very likely had prostate cancer for at least ***** years prior to detection for it to get to that stage

I have a ***** who is ***** and has just been diagnosed stage *****. He was asymptomatic, a second ***** with ***** and my ***** also has *****

Another friend aged ***** at ***** after having been refused a PSA by his GP when he was ***** because he was 'underage' and asymptomatic

A friend (*****) has just had a prostatectomy. Another case of delayed diagnosis. He was stage ***** , Gleason ***** and was asymptomatic

Two of my close neighbours (*****) are currently under active surveillance after biopsies confirmed they were stage ***** , Gleason *****

Evidence Comment:

The European Randomized Study of Screening for Prostate Cancer (ERSPC) and the evidence it generated appears to have been largely dismissed.

It ran for over 23 years and suggested an overall reduction in mortality of 13%.

Black men are at higher risk of prostate cancer, statistics show. The evidence presented appears to have been based on an American study of black men and once again seems to have been dismissed as unreliable due to socio-economic differences and resulting access to healthcare in the USA

Men with known family history of prostate cancer have not been included within the draft recommendation unless they are aware of being BRCA 1 and BRCA 2 gene mutation carriers. Not many men will know if they are or are not. A history of breast cancer and ovarian cancer within the family may suggest that they need to be tested for gene mutations, but many guys will have no idea where they stand.

My father died when I was *****. I have no idea whether or not he had any issues with his prostate. My grandfathers were *****. The female members of my family may or may not have had breast cancer or ovarian cancer or whatever. I have no idea of cancer history within our family. It simply wasn't talked about

To find out whether your are BRCA carrier is just another hurdle guys will deem to be in the way of early cancer detection. They will not bother to find out. No one will tell them

Discussion comment:

I'm not a great believer in co-incidence. The timing of the presentation of the review findings (28th Nov 2025) and first recruitment of guys to the Transform Trial (20th Nov 2025) nearly 18 months after first being announced may well tell a story.

Was the NSCs decision on PCa screening cut and dried long before they sat down around the table to discuss it?

The Transform Trial will deliver reliable science based evidence on the best method for diagnosing prostate cancer and therefore provide a firmer foundation for basing the case for screening on. So, is that what we have to wait for? Is it Transform or bust?

No doubt it will deliver, but with the results of the first phase of the study not expected for 3 years and results of the second phase for a further 10 after that, at current estimates, we are likely to see somewhere in the region of 120,000 men die before any screening GO button is pressed.

Recommendation comment:

I most certainly do.

Since my diagnosis, I have embarked on a mission to reach as many guys as possible through awareness talks and other volunteering activities.

From what I've gathered for the last couple of years, the demographic appears to be shifting and it seems many more guys in their mid 40s are being diagnosed with late stage PCa

We appear to have a growing problem with prostate issues in this country.

Although the PSA test is not infallible, it is nonetheless a pretty good indicator that further investigation may be needed.

After talking with many dozens of guys at various events, every case of prostate cancer that I have heard about have started with a PSA test

Alternatives comment:

What alternatives???

Other comments:

Introduce targeted screening for the following groups AT THE VERY LEAST

Black men 40+

White men 45+

Those with known family history

Take empirical evidence much more seriously.

Improve guidelines to GPs. Have them initiate conversations and encourage men to talk tell them to never discourage guys from having a PSA test

Affected Comment:

Prostrate Cancer has already taken my father at an early age, I have had my prostrate removed but it came back and I have had radiation but the cancer has returned and although my PSA level is rising the cancer cannot be found. My ***** died from cancer, during the last ***** months my ***** died of cancer, my ***** cancer on the ***** and my ***** has had cancerous ***** removed and had *****. I also have a ***** with an enlarged prostrate so this terrible decease has destroyed my family.

Evidence Comment:

I had the local doctor check my prostrate using the feeling examination and was told all was fine.

Clearly it wasn't as a PSA test said different, cancer was there and only found by psa test and ct scan

Discussion comment:

Unfortunately I have not due to illness been able to see the recommendations, but I do see how family's are destroyed whilst waiting around.

Recommendation comment:

I firmly believe that the PSA test is the best way forward followed by a scan as I find that quite a lot of the members of the prostrate group I attend had the same problem which proved men do not know they have this cancer. it's when they do have symptoms of bladder infections that the cancer is found, some of my group members have had severely high PSA levels and still did not know they had anything wrong.

Alternatives comment:

There needs to be a screening process for all men 50 and older and it should be repeated twice a year. The decease in the ***** of England has ***** on there doorstep and many feel that we contract the decease because of that.

Other comments:

I am from a family of ***** children, ***** , one of my brothers attended a doctors surgery requesting the PSA test and was refused,he asked at a later date for the PSA test whilst having other bloods and his wishes were not taken into consideration and then they couldn't find the results, he is *****yrs old and has a history of prostrate cancer. As luck has it he's in the clear but the story could have been quite different.

PLEASE tell doctors to stop refusing this test everyone has the right to live.

One other thing that came to light recently was that I could be carrying the braca 1 and braca 2 gene which i can pass down to my daughters which in turn can give them breast cancer, men are not informed about this and should be.

During my treatments neither a doctor or a consultant has every communicated this information for me to pass down to my children and it needs to happen so they can look after themselves.

	During my treatments I have had the prostate removed and had radiotherapy but the cancer came back I have ask if chemotherapy could be used to kill the decease instead of hormone therapy and was told no. In my case the cancer cannot be found so now I have to wait again until it can be found. There is to much waiting around and whilst chemotherapy is harsh on the body the sooner the cancer cell is killed the better, give the patient the choice of chemotherapy instead of hormone therapy.
P826	Affected Comment: My PSA tests showed a raised level and it was decided that I should have a biopsy taken. Actually, about ***** were taken and ***** were diagnosed as positive with the aggressive cancer. Soon after, (*****) my prostate was removed and as a result I am now able to tell you about it. Without this process I wouldn't be here now. My wife still has her husband and my children still have a father. Evidence Comment: No. Discussion comment: No. Recommendation comment: Due to my own experience and what I have since learnt about this dreadful disease and the dire lack of support for its detection, I desperately implore those who read this to recommend screening all men that fall within the appropriate age receive the option to have screening. Alternatives comment: Please investigate all possibilities of detecting this disease and effective methods of giving all men the chance of a full and healthy life. Other comments:

	Please don't delay. It's like a lottery and "it could be YOU".
P827	Affected Comment: My husband has Stage 4 Prostate Cancer. He had no symptoms. He was a refused a PSA test when his father aged ***** was diagnosed with Pc (no family history) but ***** years later he tried again. His PSA was shown as ***** and a very vigilant GPreferred him for further investigation. BUit had already progressed into his *****.He was ***** on diagnosis. As a result of our experience ***** friends got tested – no symptoms were present – with readings of ***** respectively. Both were deceased within *****months. No family history. My husband does not have BRCA (I fought to get him tested) PSA tests are not a silver bullet but they can undoubtedly spot an upward trend emerging on a proper screening protocol annually. The cost of late diagnosis is crippling for the NHS and usually fatal for the patient. An annual blood test is by far the most sensible and cost effective option. Under proposed guidelines he would not have been even considered for screening and neither would our ***** friends. How can that be right? Three people within a very small circle and others have joined us with varying amounts of disease. Screening should be for ALL men, just like breast and cervical screening for women. If I had the money I would take the lot of you to court for discrimination, What you propose is an insult to all men. This disease is rife – epidemic proportions – and you fiddle whilst Rome burns. Our men deserve so much better and other countries with screening in place put this one to shame. Such shortsightedness will inevitable lead to so many more unnecessary deaths. I am ashamed to be British quite frankly Evidence Comment: So there is so much evidence out there from those affected which has been missed. I suggest you visit to the Prostate Cancer forums to see what is going on in the real world. Real live people having been let down by the system, desperately seeking treatment options where it is often too late. In this country we are always late to the party and with hindsight wish we had done more. Now is your opportunity to be proactive rather than reactive. In the long term the savings to the NHS will be immense and the lives saved by early intervention will be substantial. It is a win/win. Why are you unable to see this??? A blood test annually is better than no test. And so called high risk groups only make up a small percentage of those affected given the example of the small circle of friends we have, where ***** have or had this disease, ***** of which are dead, my partner is terminal and the other ***** are in varying stages of treatment. None of us were in your so called "high risk" group, so how is your proposal a credible option??? Discussion comment:

	Please refer to the above. I cannot reiterate enough that your big idea is just not going to cover it. We have all had to fight for BRCA testing. None of the above people had it yet ***** are dead within ***** months and my husband is Stage 4. What you suggest is totally inadequate leaving most men out of the very narrow screening bands that you have come up with. It is frankly shocking, disrespectful and discriminatory. ALL OUR MEN DESERVE BETTER Recommendation comment: Screening should ABSOLUTELY be available to all men without exception for all the reasons stated above. This proposal is utterly disgusting. Alternatives comment: If the proactive preventative screening process is good enough for ALL women then it is certainly good enough for ALL men. Every man over 50 should be contacted by the GP practice to have an annual blood test, which will undoubtedly show any upward trend emerging. It isn't rocket science. There are too many of us out here badly let down and for who it is too late. A simple blood test is not a silver bullet but an upward trend becoming evident really is. Other comments: GIVE ALL MEN AN ANNUAL PSA BLOOD TEST WHICH WILL EASILY AND COST EFFECTIVELY HIGHLIGHT AN UPWARD TREND EMERGING. IT IS A WIN/WIN FOR THE NHS AND ALL OF US.
P828	Affected Comment: My father was diagnosed with stage 3 cancer opportunistically in his early *****. Despite a total prostatectomy he still has a rising PSA indicating metastases. His suspect prostate was noted by a colorectal surgeon on DRE and further investigation was recommended, but his GP never followed this up. Had there been a screening programme he may have got his diagnosis sooner, and might not have metastatic cancer. Evidence Comment: A question: has enough weight been given to the patient voice? In this instance this should be the primary driver in the decision Discussion comment: Unreasonable Recommendation comment: It should. To allay anxiety and diagnose people sooner so they can live well for longer. Alternatives comment: Grant individual requests for a PSA test when patients make them.

P829	Affected Comment: Yes close friends Recommendation comment: Screening should be recommended to ensure men feel supported and reassured Alternatives comment: More and targeted publicity that raises awareness of prostate cancer
P830	Affected Comment: This has affected my dad but of course, it affects us all. Recommendation comment: Screening should be recommended, why would we not have a screening programme for prostate cancer. A simple blood test, that can detect cancer, so it may not always be entirely accurate but in my dads case and other cases that I know of, it's detected accurately. Men are continuously being diagnosed too late, when the simple blood test could have given them a chance to not be given an incurable diagnosis. Screening will save lives. Alternatives comment: When a man requests a PSA test, it needs to be made easily accessible. So many times I hear the same thing that men are constantly being made to feel bad for asking. Doctors need to understand that this can be a symptomless disease, my dad didn't have any symptoms initially. Something so easily is made so difficult. Referrals need to be made to specialists even when the results are borderline, my dad was a missed opportunity ***** years ago. A borderline result with no symptoms and his PSA test was dismissed, had he been referred then, we would be facing a better outcome. Other comments: Education for doctors, nurses and receptionists at GP surgeries. Men are always reluctant to seek medical care, we should encourage them to go. Encouraging men who have relatives who have/had prostate cancer to get PSA tests.

P831	Affected Comment: Yes, ***** years ago I was diagnosed with prostate cancer (Gleason 4+3) following a positive PSA test, MRI and perineal biopsy. Initially I opted for an active surveillance (watch and wait) regime, but decided to have surgery last *****. I had a radical nerve-sparing prostatectomy (da Vinci robot assisted) which was 100% successful and my PSA is now ***** Evidence Comment: If there were more universal PSA screening together with more follow-up MRI and biopsies there would be more evidence and less impact of false positives. More research is needed to assess the reason for false negatives, but false negatives should not be an argument for not screening using PSA testing. Discussion comment: Thousands die because of lack of understanding of the comparative low risk of treatment vs the risk of an unnecessary, prolonged and painful death. The review is focussed too much on short-term cost impact of screening. Recommendation comment: I believe screening should be recommended and widely publicised. Prostrate cancer is generally symptomless and PSA testing is currently the only non-invasive early indicator of the disease Alternatives comment: Education and encouraging at risk men to get tested, also encouraging men's partners and relatives to get their menfolk tested. Encourage large employers to sponsor test programmes

Affected Comment:

I have had prostate cancer, and prior to my retirement I did some research on prostate cancer screening, but that is irrelevant. I am providing this feedback in a purely personal capacity. And as regards my having been a prostate cancer patient, nowadays, everybody knows somebody who has had prostate cancer.

Evidence Comment:

1. I have concerns about the numbers cited to justify the recommendations of the NSC, in particular those on the accompanying infographic. The latter quotes a figure of 20 cancers overdiagnosed. However, the definition of overdiagnosis used is 'the diagnosis of a cancer that wouldn't have gone on to cause harm in a person's lifetime.' This is not the generally accepted definition of overdiagnosis, and indeed with this definition there would be overdiagnosis in the absence of screening, since some symptomatic cancers would never have gone on to cause harm in the person's lifetime. This is likely to considerably overestimate overdiagnosis. This is a concern as in cancers for which there is already an NHS screening programme, the stricter definition of overdiagnosis applies. It would therefore appear the harms of prostate cancer screening are systematically overestimated compared to other screening programmes and potential screening programmes.
2. The method of determining this number of overdiagnosed cases is quoted as 'based on a mixture of clinical expertise and the ProtecT trial'. This is vague and suggests that the numbers lack rigour.
3. The infographic states that of 1000 men screened with a PSA test, 100 will have a positive result. However, from the accompanying text, it appears that the numbers are based on cumulative figures over four years, in which some men will receive more than one PSA test. This tends to overestimate the false positive rate.
4. In addition, it appears from the infographic that the benefit in terms of lives saved is based on invitation, whereas the harms in terms of overdiagnosis and overtreatment are estimated based on being screened. Since not all persons offered screening take up the invitation, this biases the estimate of benefit-harm balance towards harm. For a level playing field, the estimate of lives saved among those actually screened should be around 2.4 per thousand rather than 2, from the most recent ERSPC results.
5. The estimated numbers experiencing adverse effects of treatment are also slightly worrying, since they appear to be based on tumours diagnosed in an environment when treatment was rather different from today (for example, the adverse effects of surgery pertain entirely to radical prostatectomy, which no longer comprises 100% of surgical procedures).
6. It may be that after revisiting the numbers, the NSC comes to the same conclusion. However, it would then hopefully be based on more rigorous empirical observations.

Discussion comment:

7. As regards the recommendation for screening in those with BRCA1 or BRCA2 mutations, I could find no persuasive evidence that BRCA1 has similar implications for risk of prostate cancer or 'clinically significant' prostate cancer to BRCA2. Indeed, I could find plenty of evidence

	that it does not. If this recommendation is to remain, what is the evidence that BRCA1 and BRCA2 have similar effects on prostate cancer risk? 8. There is a concern about inequalities in relation to this recommendation, as it is likely that more deprived populations will have lesser ascertainment of BRCA status. 9. Two more general points are worth making. First, the justification given for the overall recommendation against screening is that it would do more harm than good. How is this determined. How does the committee weight a certain number treated unnecessarily against another (likely smaller) number having their lives saved? Some more rigour here would be helpful. Recommendation comment: 10. The second general point is that the balance of risks with screening and risks with not screening is a complex one, which does mean that a subjective judgement call as referred to in point 9 above is inevitable. However, it also means that a blanket recommendation for screening for all men or against screening for all men (with the possible exception of a tiny minority with BRCA mutation identified) is perhaps inappropriate. It seems to me that the Secretary of State, officials of the DHSC and the service need to devise a more complex (unfortunately) protocol of availability or otherwise of prostate cancer screening.
P833	Affected Comment: A good friend of mine seemingly healthy recently undertook the routine screening and was found to have raised levels in his blood indicating he was at risk of Prostate Cancer. Upon further investigation, it was found he did infact have the start of prostate cancer. It was identified early enough to intervene and he has had a procedure to remove it and is now in recovery. I had the test recently – mine was negative and it has helped my mental health to not feel so anxious about it. Recommendation comment: It should be recommended because of the story above and also there is an impact to men's mental health in the absence of any screening particularly as so many men are affected as there is always the 'what if' Women enjoy the security of cervical screening to help ffer assurances,men now no longer have the same benefit.

Affected Comment:

Yes, I was diagnosed with Gleeson Group 2 cancer in *****, although my PSA test were raised from *****.

Evidence Comment:

It appears that the evidence considered for the review was quantitative and not qualitative.

The review concludes that over-diagnosis and overtreatment would occur if a screening programme were to proceed and that the probability of side effects arising from treatment was also high, those side effects providing lifelong reduction in quality of life.

What appears to have been omitted from the review is patient-based evidence relating to how they view their testing, diagnosis and treatment.

I would suspect that many men would be prepared to proceed with treatment if they were diagnosed and made fully aware of treatment consequences. However, this choice is being taken out of their hands by the researches who have probably never been in the position of being diagnosed with cancer.

My circumstances were such that after being diagnosed (by MRI and biopsy) with Gleeson group 2 (3+4) cancer I was told that no treatment was available. This was due to previous ***** surgery, many years prior to the diagnosis.

My consultant at the time, presumably to allay my concern, advised that current data suggested that I would have an *****% chance of reaching the age of *****. But of course, there was a *****% chance that I would not.

When asked what would happen with future treatment as the cancer progressed, I as advised I would be given hormone treatment and then chemotherapy. This was not very comforting and, of course, I may die of another cause before the Prostate cancer took its toll.

From a Prostate Cancer patients' perspective, I am glad that the diagnosis was made early enough for me to make a choice in my treatment. As it happens, I was referred (at my request) to an eminent prostate cancer specialist which resulted in me receiving treatment by *****. This took place approximately ***** years ago with only minimal side effects.

The significant point is that I had the choice. It was not at all comforting to know that I had an *****% chance of reaching ***** years of age. From my perspective I had the thought I would be going into my old age knowing that I would, at some stage, have chemotherapy with all the side effects that that would entail, not a great thought.

Discussion comment:

One of the main reasons for not recommending a national screening programme was due to the incidence of overdiagnosis and overtreatment. However, within Section 6 of the "Accompanying Narrative" the researchers admit (section 6) " Feedback from experts supported the modelling work but raised and emphasised outstanding concerns about data reliability, GGG score accuracy, and the need to better explain overdiagnosis risks."

Recommendation comment:

	I believe there should be a Prostate Cancer screening programme to give men the choice of how they should proceed with their healthcare, this may be to adopt a “wait and see” approach or elect to have further tests and / or treatment. The “Accompanying Narrative” makes it clear that overdiagnosis and particularly overtreatment is a significant risk, but nevertheless the patient should have the right to make this choice and should do so, from an educated perspective. It is therefore imperative that education programmes are in place to provide information, so that should a diagnosis be made, the implications of treatment are already known, an informed patient would make a more informed decision. Alternatives comment: I would be sceptical if there could be an alternative to a screening programme. The only other option would be to run an education programme over multiple forms of media but would this general sufficient level of uptake, how effective have awareness programmes been in the past? Other comments: No
P835	Affected Comment: One friend of mine died of prostate cancer. Recommendation comment: Yes absolutely. I understand man can ask their GP for a PSA test, but only if they know about the basics of prostate cancer or other prostate-related diseases. GPs seem to be trained to not give PSA tests so the process can be frustrating. In the meantime, many men received their diagnosis too late for a curable treatments. Many families lose their loved ones due to this cruel condition. The situation needs to be changed and that’s why a national screening is needed. PSA test may not be the ideal diagnostic tool but it’s a good starting point nevertheless.
P836	Affected Comment: Several members of family and friends have had the condition. One died last year Recommendation comment:

	Yes absolutely Alternatives comment: Walk in testing centres
P837	Affected Comment: No Recommendation comment: Should be screening to save lives
P838	Affected Comment: Affected too many friends some who sadly passed away far too soon and more recently some friends after major surgery in recovery and the system really does require early diagnosis and treatment much sooner ! Evidence Comment: Nothing comes to mind Discussion comment: Not really and appreciate funds are limited Recommendation comment: Early screening of simply test can be delivered would be helpful or better education in the type of diet recommended would be good Alternatives comment: As above Other comments: Not at this stage but to press the government for more funding
P839	Affected Comment: My friends. Recommendation comment:

	Should be recommended. I have a husband and son as well as other male family and friends, it would be hugely beneficial to have screening and catch signs early to ensure care & treatment Alternatives comment: Education, communication etc Other comments: No
P840	Affected Comment: Friends Recommendation comment: Screening should be recommended and funding for improving screening should be prioritised
P841	Affected Comment: As a result of a PSA test in ***** and ***** arranged through the charity ***** it was discovered that my PSA level had increased substantially. I had no symptoms whatsoever that anything was amiss. Following further tests I was diagnosed with Prostate cancer. Treatment followed and touch wood following annual PSA tests, my condition has stabilised and I can at age ***** Ycontinue to work and contribute to society. Everyone needs to know their basic PSA level so that any changes can be investigated. A PSA test is the best way, at the moment, of detecting prostate cancer problems and if caught early can be treated for a full recovery. Much cheaper than treating patients with the advanced disease. Evidence Comment: Caught early, prostate cancer can be dealt with. PSA testing has saved my life. Discussion comment: Yes, some people have a higher risk than others but all men should know their basic PSA level so that any changes can be investigated. Recommendation comment: Screening should be available to all men in the same way that breast and cervical screening is available to women. Alternatives comment:

	People with prostate cancer can have no symptoms until the disease is advanced. Hundreds of men are walking around not knowing that they have this disease. PSA testing would give men a fighting chance against this silent killer. Other comments: Make PSA available to all men from 40 years old and test every five years thereafter.
P842	Affected Comment: Yes. Friends and family Evidence Comment: No Discussion comment: No Recommendation comment: Yes. Since it's the biggest cause of cancer deaths in men there should be equality with the level of importance given to the screening g of breast cancer in females. Alternatives comment: Screening is the priority Other comments: No ☐ ☐
P843	Affected Comment: Affected several friends

	Recommendation comment: Screening should be pushed by the government far more
P844	Affected Comment: Yes, I have friends who have died and others who are currently on heightened monitoring Evidence Comment: No Discussion comment: No Recommendation comment: Yes, but I appreciate the cost/benefit issue Alternatives comment: Increased awareness of risk, early symptoms etc Other comments: No
P845	Affected Comment: Father-in-law had prostate cancer. Recommendation comment: Yes, screening should be offered. Prevention is better than cure. Catch it early and save lives.

Affected Comment:

I was diagnosed at the age of ***** with stage 3 prostate cancer in ***** and had a RARP procedure in ***** of that year as my prostate was overwhelmed with cancerous cells and significant tumours that were about to metastasize. I was asymptomatic – and am now suffering from ED post surgery, am aware that there was creep of cancer along the urethra to the bladder (which though excised) leaves me at further risk.

The only reason this got picked up was because I insisted on a PSA blood test every year from ***** years of age because there was family history – my father had been diagnosed with stage 2 prostate cancer (he received localized radiotherapy) when he was in his ***** some ***** years ago.

This has caused much anxiety and worrying – i have ***** sons – the risk they carry now is 1 in 2!!! Yet there is no screening program that can help them identify if they are greater risk of developing prostate cancer when they are at the appropriate age. I have checked for BRCA 1 & 2 genes and I do not carry them – but the family history shows that with 2 paternal generations having prostate cancer they are at the highest risk.

The NSC needs to review their judgment – how can men with a family history and risk of developing cancer as 1 in 2 be excluded from a national screening program?!

S.E Asian people of my fathers generation do not talk about such illnesses. This makes informing other generations a real issue – the lack of awareness and screening in the Indian sub-continent people is a further risk – especially where there is family history. My own father hadn't even told me till several years after he was diagnosed!

Evidence Comment:

Family history has been ignored by the NSC in the review.

My father had been diagnosed with stage 2 prostate cancer (he received localized radiotherapy) when he was in his ***** some ***** years ago. He was asymptomatic and was found incidentally when he was tested for overactive bladder.

I was diagnosed at the age of ***** with stage 3 prostate cancer in ***** and had a RARP procedure in ***** of that year. I was asymptomatic.

With ***** sons – the risk they carry now is 1 in 2!!! Yet there is no screening program that can help them identify if they are greater risk of developing prostate cancer when they are at the appropriate age. I have checked for BRCA 1 & 2 genes and I do not carry them – but the family history shows that with 2 paternal generations having prostate cancer they are at the highest risk.

How would BRCA testing have helped in this situation from preventing cancer taking root? How would men even know their BRCA status?

I implore the NSC to revisit their decision – men with family history must be part of the national screening program.

Discussion comment:

The conclusions feel overly cautious and ignore men at high risk because of ethnicity or family history – or both. In the face of rising diagnoses – with the tools urologists have, increased diagnosis does not equate to over treatment or increased side effects from the diagnostic protocol. The alternative side effects of late or missed (because of no screening for the cohorts who need it most) is almost certainly death. How is that justified?

Black men and those with family history if diagnosed earlier can mean that late stage presentations can be reduced (if the cancers are caught at earlier stages where they are more treatable) = more men diagnosed earlier live longer.

The positive impact of this at family levels is incalculable – families and not destroyed due to the impact of late stage diagnosis or the premature death of a man, who might have been saved had he been tested earlier.

The cost of treating a stage 4 patient for as long as they survive is vastly greater than a screening program that identifies and treats patients at earlier stages...where the men may still be able to work and have meaningful family life and contribute to society.

Recommendation comment:

Targeted or risk-based screening is a sensible first step – men at higher risk deserve earlier assessment and clearer pathways for testing to treatment – where needed. Ignoring men with family history or black men who are known to have increased risk is tantamount to being unequal in assessing ALL men at risk.

The debate of overdiagnosis or overtreatment is valid – but i believe that the modern tools urologists have with effective mpMRI, robot and computer assisted treatment options the increased rate of diagnosis (which is inevitable as so many men are not diagnosed till too late) does not equate to over treatment or increased side effects – when decision making for treatment is taken with the patient.

ask yourself a question if you were a man in the high risk category, given the choice, would you rather be:

(A) a man who is diagnosed late with metastatic prostate cancer who has no cure option and the finality of your (premature) demise is determined, or

(B) a man who potentially gets diagnosed at an earlier stage of prostate cancer that is treatable where you might be able to live your life to the expected age albeit with some possible treatment related issues.

I would expect everyone would select Option B

Alternatives comment:

I would suggest organised prostate cancer testing instead of the current ad hoc system, earlier risk assessment for higher risk men, clearer access to PSA testing, better GP support and education, improved public information, and action to tackle inequalities in access and outcomes – especially targeting black and SE Asian communities – who are noted as being less diagnosed and more unaware of the dangers of late stage prostate cancer diagnosis.

Other comments:

	I think there is a need to keep policy under active review as new evidence emerges rather than waiting every 2,3 or 5 years to re-review the NSC findings. It is very important to involve patients and different ethnic community representatives in future decisions – this will help get root level support for initiatives which hopefully will make them more successful. I understand as a patient and ***** that while screening decisions are complex the committee must take into consideration lived experience to be considered alongside clinical evidence. The evidence that family history and being of black ethnicity are real factors that impact onset and more aggressive prostate cancer profiles should be included in any screening program. As a son, whose father had prostate cancer – and a father of ***** sons, I am worried beyond what words can articulate, at the risk of a 3rd generation of men (of a family with known prostate cancer history) developing prostate cancer – if they are not screened regularly. The need for urgency while remaining evidence led should not be lost. PLEASE reconsider and include men at high risk in a screening program for it to be truly effective.
P847	Affected Comment: I'm ***** post prostatectomy, turned ***** last year, no symptoms, super fit and healthy, went for a PSA on the back of a friend being diagnosed. It's crucial that a screening programme is put in place. On my first hospital visit I was told, with all my metrics that's there was a*****% chance I didn't have cancer, they were swithering whether to send me for an MRI – ***** I'm glad I pushed for an MRI. Recommendation comment: Yes I do – for all the reasons above. Other comments: Don't lead people to believe they might not have cancer. I have been in ***** for ***** years and see the wastage in the NHS – a brilliant service when you need it – of the NHS was run efficiently there would be more than enough surplus to offer a screening programme and solve a lot of the other issues.

Affected Comment:

I am a Prostate Cancer Patient. My father also suffered and died from Prostate Cancer. I had regular PSA tests because my father had died from Prostate Cancer. Due to the position of the cancer my cancer was not diagnosed until it had started to break out of the capsule. A screening program including other tests in addition to the PSA and DRE tests might have detected the cancer earlier, and allowed the cancerous prostate to be removed. I am still living with my cancerous prostate due to a later diagnosis than would have been ideal.

Evidence Comment:

Whilst all screening processes can produce incorrect results PSA testing is not in itself a diagnostic tool. It can however identify men who if they have two consecutive PSA tests where the PSA is raised would need further testing. The first of these further tests would generally be an MRI scan – non invasive. If this scan showed concerns then a biopsy would be suggested – ie the first invasive test for a suspected Prostate Cancer would be the third test a patient would undergo. The pathway being PSA – MRI – Biopsy.

Discussion comment:

The discussion talks about too many men undergoing invasive tests. As mentioned above the pathway to diagnosis is generally PSA – MRI – Biopsy. ie a large number of men would not need invasive biopsies. It should further be pointed out that biopsies tend to be Trans-perineal biopsies these days rather than the older trans-rectal biopsies. These more modern ones carry much less risk of infection than the older trans-rectal route. The committee also made a lot of noise about men being over treated who do not need treating. What about all the men who are under treated, their cancer is detected after it has metastasised and can only have their cancer treated without chance of a cure. This late diagnosis leads to far, far more brutal and debilitating treatment which must cost the NHS a excess money compared to earlier, less brutal treatment.

Recommendation comment:

Yes, I feel screening should be offered to the groups of men identified as being most at risk of Prostate Cancer. These groups being Black Men and Men with a family history of Prostate Cancer. These groups tend to have a 1 in 4 ie any man in these two groups has a 25% chance of developing this horrible disease. It is less costly to screen, diagnose and treat with curative intent than to not screen, and diagnose after the cancer has spread and need more brutal treatment, without curative intent, only palliative intent.

Alternatives comment:

The government could help people with this condition by training and employing more Doctors, Surgeons Therapy Radiographers and all the staff needed to run these services. The government could also help by making more operations, radiotherapy sessions available. The government could also fund the use of newer, more expensive drugs earlier which will be needed as more people will be diagnosed with late stage Prostate Cancer due to a lack of a screening program. Funds to help with transport costs could also be considered as radiotherapy is not carried out in all hospitals – only specialist hospitals. In rural areas patients can have over an hours journey each way to reach a hospital that performs radiotherapy

Other comments:

	If you do not agree to a screening program that all Prostate Cancer charities recommend ie to those men with a family history of the disease and black men then review the recommendations every year
P849	Affected Comment: Yes un certainty of where my life goes has turned everything up side down Evidence Comment: I had no symptoms Discussion comment: Just agree to a screening program Recommendation comment: Should be
P850	Affected Comment: Yes. I had no symptoms but requested a PSA test. It found a level that needed monitoring. Subsequent tests gave increasing 'scores' and when given the choice I opted to have my prostate removed. Regular tests in the ***** years since have shown levels to be undetectable. Many have no symptoms and should be screened, as are ladies for breast cancer. Recommendation comment: Yes. Because when symptoms appear the disease could have started to spread. The earlier it is caught the greater the chance of a cure and less burden on the NHS.

P851

Affected Comment:

I have been living with prostate cancer for ***** years. I was asymptomatic when diagnosed, where by good fortune I saw a charity PSA testing event that lead to my diagnosis just before the cancer became metastatic.

I want other men to have the benefit of early diagnosis, with less invasive treatment pathways and with enhanced longevity and life quality.

Evidence Comment:

There is a key societal issue that must be taken into consideration.

Men, and particularly those of African Caribbean heritage, can be reluctant to approach their GP. Early symptoms of prostate cancer such as discomfort passing water, or being up 2 or 3 times per night to do so, are often dismissed as a sign of aging.

As the symptoms grow, men are likely to consider consulting a GP but not as a priority – sometimes due to the fear of 'bad news'.

By the time a GP is consulted, the cancer may have developed to the point of being metastatic. Some 45% of prostate cancer diagnoses in England are already at advanced stage.

Discussion comment:

If the PSA test, albeit not a direct cancer test, is indeed as unreliable as some senior clinicians believe, then why is it offered to men with the BRCA1/2 genetic condition rather than being banned altogether?

It is essential that all high risk groups are considered equally, primarily: * Family history of prostate, breast or ovarian cancer. * African Caribbean heritage * Possible symptoms already in place.

Note that a single PSA test will not lead to a man being over-diagnosed and over-treated. A high PSA reading would normally be followed by a follow up test, to identify any trend, then a DRE (itself not perfect) and scans, before proceeding to invasive biopsy.

Recommendation comment:

I recommend that screening should commence at an early stage, at least for all high risk groups (so as not to overwhelm the NHS capacity). The PSA test takes just a couple of minutes in a hospital pathlab.

Where some clinicians reject the PSA test, and where GPs decline to provide the test to patients who ask, they are effectively saying "Come back when you have symptoms". This is surely intolerable,

The need for earlier diagnosis is recognised by the Prime Minister, Health Secretary, Deputy Prime Minister, Lord Cameron, Riski Sunak, Sir Chris Hoy, Sir Stephen Fry and others.

Alternatives comment:

	There are currently no alternative screening tools for prostate cancer, and the PSA test is simple and low-cost. The NHS and Government have a key role in cancer awareness, not least because so few people understand the high risk factors and symptoms. This role extends to many medical conditions but prostate cancer is clearly the most frequent cancer experienced by men (and trans women). Other comments: The context of prostate cancer must be recognised: today, like yesterday and tomorrow, some 30 men will die from prostate cancer, many of whom could have benefitted from earlier diagnosis. The NHS would have benefitted by reduced levels of more invasive and expensive treatments and clinicians' time. Thankyou.
P852	Affected Comment: Yes. I was diagnosed with prostate cancer in *****. Evidence Comment: I could not determine whether the effect of age and extent of the disease at diagnosis is taken into account when considering the cost of treatment. An early diagnosis will lead to less invasive surgery and a reduced chance of ED, incontinence problems etc. There will be less cost to the NHS. A later diagnosis, when the disease has spread beyond the prostate and possibly surrounding nerves, leads to more more life changing complications. Therefore the earlier the diagnosis, whether false or not, the better the outcomes. Discussion comment: I think the conclusion that targeted screening should be introduced is a step forward, but the introduction of limiting screening to men with certain BRCA genes will only bring confusion and reduce the number of men coming forward for screening. I am ***** years old and have no idea of my BRCA status.

	My father died at *****, before he had the chance to develop prostate cancer, so my family history is not a “red flag”. There needs to be a screening programme, or at least a national awareness programme, to identify men with the relevant BRCA gene and other “high risk” factors. Recommendation comment: Screening should be offered based upon age to give men the knowledge to make their own decision on further investigation and treatment. Improvements in MRI screening will reduce the number of false positives. Alternatives comment: An awareness programme publicising who is at most at risk, and instructions advising GP’s to support that decision, not obstruct it. Other comments: My diagnosis was made following a random psa test. I feel that if I had been diagnosed 12 or 18 months earlier my treatment would have been less invasive, and would have been at less cost to the NHS.
P853	Affected Comment: I was diagnosed with prostate cancer on ***** with a PSA of *****. Staged as ***** Grade group5. Locally advanced and very aggressive cancer. I am currently undergoing radiotherapy, ADT, and Abiraterone. I am ***** years old. I fall into none of the risk groups. It was only discovered because during a routine check-up I asked my GP to add PSA to the several other blood tests. This was initially met with some reluctance, but I insisted. This was possibly the best decision of my life. Without that PSA test I would have remained ignorant of my condition. Judging from my diagnosis I would have most likely been dead within 5 years. Hopefully now I can expect a full lifespan. Evidence Comment: The sensitivity and specificity of the PSA test is often quoted as being inadequate to be used as a mass screening tool. My wife, a *****, checked the research data on this. She points out that the cut off points used for triggering action could be adjusted to give a better result than what is currently achieved, with fewer false positives. Discussion comment: It is often cited that PSA testing leads to over diagnosis and unnecessary interventions. This assumes that a raised PSA result necessarily leads to intervention.

In my view a PSA result should be seen as a marker only leading to further tests and interventions if deemed appropriate by the overseeing medical team.

With MRI scanning now widespread this should be the next recourse with biopsy only considered if indicated as necessary.

On the subject of side effects, in my experience these have been fairly mild and bearable so far. The major issue being fatigue from the ADT. While this is an inconvenience it is a small price to pay considering the alternative of no treatment.

The biopsy although undignified is much exaggerated as a reason to not test. It's a good deal less objectionable than a major session at the dentist.

The inclusion of BRCA 1/2 gene variants as a cue for targeted screening is faintly ridiculous. Just how many men would this apply to? I insisted that my biopsy samples were to be sent for genetic testing. Note: I had to insist, this testing was not done as a matter of course.

I am finding that this is a long and convoluted process and ***** I am still awaiting results.

Recommendation comment:

Most definitely yes.

With no screening programme, men such as myself, are left to chance and the whim of often reluctant GPs. In my case it was reading an article in the press and my insistence that a PSA test be done. My cancer could easily have been missed up to the point that no curative treatment could be offered.

As I have stated above, I fit into none of the groups being considered for targeted screening.

Alternatives comment:

There are no practical alternatives to a screening programme without the outcome that many men in my condition will slip through the net and suffer the consequences of a late diagnosis.

It is true that most men will die with rather than of prostate cancer, but for a significant minority of cases, my own included, this disease is far more serious. What is to be done for these men? An absence of screening will condemn them to an early death.

I hope that a successor to the PSA test will rapidly become available, and there seems to be several promising candidates just over the horizon. But, in the meantime we must press ahead with the only current, affordable test we have. I feel that with a little more thought the test can become a useful indicator. Let's not throw out the good for want of the perfect.

Knowledge of what is happening deep inside your own body is paramount, enabling an informed decision on what steps (if any) are to be taken.

In my own case I was referred to my local Urology Department for another matter some three years previous to my eventual diagnosis. I believe that this was an opportunity missed. Any man referred to Urology, for whatever reason, who is within the target age, should routinely receive a PSA test.

If it is decided that testing should only be made available to targeted groups, admission to a Urology department should be one of the target criteria.

Other comments:

The current guidance to GPs is that they should not 'actively promote' PSA testing. It is my experience that many GPs take this guidance far too literally and possibly go beyond the guidance into discouragement.

There is an absence of any literature or guidance on Prostate Cancer seen in GP surgery waiting rooms.

This is in stark contrast to women specific cancers, Cervical, Ovarian and Breast, are widely promoted via posters and leaflets.

This is wrong and the guidance to GPs should be revised.

Since my diagnosis I have suggested to several friends that they should ask to have a PSA test. In two instances, to my knowledge, the request has been met with a refusal by their GP.

This is not acceptable and must change.

Affected Comment:

My father was diagnosed with prostate cancer when he was in his early eighties (about *****). On the advice of my physiotherapist, I asked for a PSA test in ***** and was subsequently diagnosed. I was ***** y old and although had a disease on the border of Stages 3 and 4, had no symptoms. My disease was very aggressive when discovered (Gleason 9) and had spread into *****. I had intensive treatment (surgery, hormone treatment, chemotherapy and radiotherapy) and thankfully am now disease free. I was told that had I waited another 6 months before visiting my GP, my prospects of a cure would have been greatly diminished.

Evidence Comment:

Although I have science background, I am not a medical expert. The comments in the NSC Report on of the accuracy of the standard PSA test are well-known, but as I understand it, using the test repeatedly for men over 50y as part of a screening programme, for example to look for significant and unexplained increases over a few years, is much less prone to 'false positives'. Together with more time-efficient MRI scans being developed, I would think that this approach would be sufficiently cost-effective ('cost' in the wider sense of diagnostic and treatment side-effects) to be worthy of closer analysis than just repeating the case that PSA tests are insufficiently accurate to be used as a screening tool.

The argument for using PSA as part of a screening setup is of course strengthened for black men and (as in my case) men with a family history of the disease. I had a genetic test and this concluded that I had a relative risk (compared to the UK average) of over *****; though this was due to a collection of discrete DNA errors, not due to gene variants such as BRCA 1&2. This is much higher than the accepted risk increase due to family history. The NSC Report makes the comment that even with the admitted higher risk from family history, the 'high level of uncertainty' would still rule out a screening programme as it would lead to overdiagnosis and overtreatment. See my comments above of repeating PSA tests and using emerging scans such as the 'short MRI'.

Discussion comment:

I am frankly surprised at the conclusions of the review, which seem far too cautious given the severity of the risks presented by this cruel disease.

On the subject of black men (I am white), I am shocked that a theoretical risk of cancer of about 25% is apparently insufficient to 'work around' the uncertainty in the PSA test reported.

I am active in the prostate cancer support community (which is mainly white) and have noted that most men did not experience any symptoms before diagnosis, and were discovered 'by chance', which seems very unsatisfactory to me.

Recommendation comment:

I feel strongly that screening, in some form – not necessarily a one-off PSA test in isolation – should be introduced in the UK as a first step. Risk-based screening is key, and would be justified for black men, men with a family history and those with evidence or suggestion of a relevant genetic condition that could elevate their risk significantly.

Alternatives comment:

	I have heard of many, many instances of men being turned away from further investigation by GPs on the basis of their having no symptoms, even when they have a relevant family history. In my experience this is a massive block on starting a rational conversation on risks more widely. Also, men who are over 50 y are entitled to having a test (=series of tests) in the UK, regardless of what their GP thinks, and this is something that should be more well known. Improved public education on prostate cancer would also be very valuable. Circulated literature should not focus on symptoms, as many leaflets do, unfortunately, giving the misleading impression that being symptom-free means that one is unlikely to have cancer. Other comments: The UK policy on national screening for prostate cancer should be kept under review, and be responsive to medical (diagnostic) improvements, rather than waiting up to 5 years (for example). The need to reduce the toll of prostate cancer by catching it earlier, enabling a cure, is urgent. Even if a comprehensive screening programme ensuring a net benefit is not yet possible, every means should be explored to minimise the likelihood of late detection. 'Prostate health' should be included as a topic on NHS regular health checkups for men. Finally, while decisions on screening are clearly more complex than often seem on first examination, I feel very unhappy that my own, near-fatal diagnosis – at one stage I was told that I could not have radical radiotherapy as my tumours were too widely separated – came about solely from the suggestion from my physiotherapist to visit my GP. As a result, I will ensure that my sons do not make the same mistake. Other men in a similar situation, along with their families, surely deserve better from our health care system.
P855	Affected Comment: Prostate cancer has affected my immediate family and several friends. My own status is stable at present but obviously I wish to be aware of any changes. In my own case I have PSA tests to monitor the situation. Whilst it may not be a perfect solution, the peace of mind is of huge value to my general well-being. Recommendation comment: Recommended. I feel it is better to be aware of the situation – even if no action is required – rather than leave it too late. It is the most common cancer to affect the male population. Some men are more susceptible than others Alternatives comment: General awareness campaigns – symptoms, risk factors, the nature of the disease etc. that are country-wide – so that all men receive the same basic information without local variations.

P856	Affected Comment: Yes, I was diagnosed with advanced prostate cancer in *****. My older brother had a prostatectomy a couple of years later and then my younger brother had treatment a couple of years after that. Evidence Comment: If I had reported my symptoms earlier I might have been diagnosed earlier. Discussion comment: I believe it would be useful that screening should be offered to all men. Recommendation comment: It should be recommended followed by mri/ct scans where a problem arises. Alternatives comment: Better education and publicity of the condition.
P857	Affected Comment: I was diagnosed ***** years ago (PSA *****) and treated ***** years ago (external beam radiotherapy, HDR Brachytherapy, and 2 years ADT). So far, no recurrence. Also pleased to report, no significant side effects, and urinary function, bowel function, and sexual function are all normal. This is a much better outcome than I ever imagined at the beginning. By chance, I noticed a charity PSA test event, attended, and the result from that came back unexpectedly high – I had no symptoms and very regularly exercised, so I was very fit, and not the sort of person I imagined was likely to get cancer. (Of course, I now know that prostate cancer isn't a lifestyle cancer, and hence many very healthy people are surprised to get it, and 80% of those diagnosed never had any symptoms of the cancer.) I am all too well aware how my situation could so easily have been much worse if I hadn't been diagnosed until a bit later – I was close to being metastatic. (Indeed, they spent some time assuming I was metastatic and trying to find where it was during my diagnosis.) As a result of becoming an expert patient during my diagnosis and finding I really enjoy helping other patients, I retired and now *****. I have *****. Several *****. I have also *****. Bizarre as this sounds, I really enjoy this voluntary work, and I'm currently pleased life sent me in this direction. My family are proud of the work I do. Having said that, I'm only too aware I was diagnosed as an extra high risk case, and there is a chance it could return although everything is looking as good as it could be at the moment. Evidence Comment: Contrary to the suggestion in the report, most men have no idea of their BRCA mutation status, and there won't be any record of it. (I have spoken with probably thousands of men diagnosed.) Although a BRCA mutation significantly increases the risk of PCa, it still accounts for a small

percentage of cases and won't make much difference even if you could find them all, which there's currently no viable way of doing. So the NSC's decision just didn't make sense.

There has been a very heavy bias towards worrying about harms of testing and over-treatment. Conversely, there has been next to no consideration about the harms of not testing, resulting in men stuck on reduced QoL life-long treatments, and dying prematurely, who could have been cured if caught earlier. I come across many such men in support groups, and recently attended a funeral of this cause. This has an ongoing massive impact on their families too. I would be in this situation now if my PSA hadn't been checked until 1 or 2 years later, and I would be pre-deceasing my parents which, *****, would have been very tragic for them.

Prostate cancer diagnoses are not accurate with respect to Gleason and Staging. 40% of post-prostatectomy pathologies show the original diagnosis to have been incorrect, mostly under-diagnosed. Many men offered a choice of Active Surveillance or prostatectomy who chose prostatectomy are subsequently found to have been under-diagnosed and not suitable for Active Surveillance. NIHR said in a talk a year ago that 30% of men on Active Surveillance are under-diagnosed to the extent they shouldn't be on Active Surveillance. Hence it cannot be said that all those diagnosed as Gleason 3+3 who chose active treatment over Active Surveillance were over-treated, as there is currently a strong tendency to do, as a significant proportion of them have been under-diagnosed and should be having active treatment. A 30% chance you've been under-diagnosed isn't going to match everyone's risk appetite for Active Surveillance. The ProtecT trial showed you are twice as likely to later end up metastatic if you choose Active Surveillance over active treatment.

Getting diagnosed while you are still curable shouldn't be by chance. I now know many men through my support activities who missed that chance. Men in lower socioeconomic groups, who are coincidentally at a higher risk anyway, are less likely to know they need to ask for periodic PSA tests to reduce their chance of dying from prostate cancer.

Discussion comment:

I don't believe screening can wait until TRANSFORM reports in 5, 10, or 20 years time. That's an awful lot of metastatic men and deaths which were avoidable.

TRANSFORM is important, but must not delay screening. Screening can run in parallel and adapt as TRANSFORM produces outputs.

Recommendation comment:

If there's a disease which shows no symptoms in 80% of those diagnosed, and which is usually easily cured when caught early, but fatal when caught too late, the only alternative to screening is thousands of avoidable deaths, and many more thousands of children, partners, and even parents impacted by the loss of a loved one. There's usually a lifelong impact on life opportunities for children who lose their fathers, and the impact is even more harsh in the lower socioeconomic communities which are in any case at a higher risk of prostate cancer. This simply can't continue wreaking havoc in these communities as it does today,

Alternatives comment:

The NHS has repeatedly shown that it can't afford to treat men who have been diagnosed too late and become metastatic, and who cost vastly more than the cost of curing a man caught earlier. Hence the drugs required for advanced disease don't get approved for use at the

	appropriate time in the treatment pathway, or it takes years to happen and thousands of men (and their families) miss out. We can't afford to miss the opportunities to cure a man. The alternative to screening is expensive drugs to keep more metastatic men alive for longer, and with a poorer QoL. It's also children prematurely losing fathers, wives prematurely losing their lifelong husbands, and even men pre-deceasing their parents for whom some are carers (could have been my case if caught only a bit later).
P858	Affected Comment: I have advanced prostate cancer and have been on ADT and hormone therapy for ***** months. This treatment is costing the NHS thousands of pounds. This could have been avoided if screening was available. I am now concerned for my son and grandson going forward Recommendation comment: It should definitely be recommended in my lifetime

P859

Affected Comment:

If I had been prostate screened before my cancer diagnosis in ***** it would have stopped my cancer from spreading and treatment could have started earlier.

I wss admitted to ***** with renal failure.

Over ***** years down the road I face urinary incontinence and annual operation to replace my bilateral uretic stents which always has a kick back and needs recovery time.

I also developed sepsis in ***** and had a ***** in *****. In short my quality of life is much deteriorated.

However I get well looked after by *****

My PSA is undetectable.

My cancer condition has drastically affected my social life and activities. I also have some *****.

However I keep positive most of the time

Evidence Comment:

When I was admitted to ***** with renal failure they told me that they had missed a shadow on a scan of my kidneys. I have never heard anything more about this despite enquiring.

Overall ***** has managed my illness well.

Discussion comment:

No other than screening is necessary for prevention of advanced prostate cancer

Recommendation comment:

Prevention as in the long term it will lead to improved lifestyle and save the NHS money.

Screening is necessary

Alternatives comment:

More resources devoted to cancer diagnosis and after care.

I use ***** for cancer support and various other activities. I have met many great 🧑 people and we support each other.

Other comments:

No

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Affected Comment:

I was diagnosed with prostate cancer in *****. I was referred to ***** Hospital and had a prostatectomy as the tumour found was aggressive. It had spread and *****. I was thus started on ADT and an ARPI was added.

I had recovered well after surgery, had no incontinence problems and even had some return of erectile function. The ADT though had, and continues to have profound effects. All my life my blood pressure had been on the healthy low side of normal. It rose on the new medication and I now have to take medication to control it. I was also diagnosed with ***** at my pre-operative assessment. This condition is made worse by the medication. I had to stop taking the Enzalutamide, which gave some relief, though it may mean the cancer becomes castration resistant at an earlier stage than if I had been able to tolerate the Enzalutamide or other ARPI.

I had always led an active life, but have noticed a significant loss of strength and stamina. DEXA scan has shown some osteopenia and I am taking Alendronic acid, which has its own set of issues. Fortunately *****, so I have not been too badly affected financially.

I did do *****, which I enjoyed greatly but had to give this up, as I would not have the strength to *****. I also have not *****. Fatigue is a common problem and I would become a *****. ***** was a big part of my previous life. I was a volunteer with *****, though have not been able to maintain this. I am also a ***** volunteer *****. I still do this, but with reduced hours and a slower work rate. In short I am less useful to society as a direct result of my ADT.

My sex life is a thing of the past. ADT has taken away both my sexual ability and my libido. This is a difficult thing for any man, and the fact that the treatment which is, for the time being, keeping my cancer quiet, is also impacting on my quality of life is not easy to live with.

I am more irritable now, though I try not to be. This unfortunately impacts on my family life. They deserve better.

Evidence Comment:

I think the issue of overtreatment is based on out of date methods. My surgeon emphasised that the images from the new generation of MRI scanners has made diagnosis much more accurate. A Trans-perinium biopsy is no fun for anyone, but would appear to be less traumatic and have less harmful after effects than earlier methods. High quality MRI images also give more precise targeting of the biopsy samples.

Discussion comment:

I have a variant on the BRCA2 gene. I thus would have been eligible for annual PSA testing. However, I had no idea that I had this gene until some time after surgery, when my tumour had been genetically tested, and I was subsequently offered a blood test to confirm this was inherited. How many men have these BRCA gene variants but will not be tested because they do not know? My genetics counsellor informed me that tumours have only routinely been tested in recent years. It will take many generations before most gene carriers are aware. Both my parents lived into their ***** and neither had cancer.

Recommendation comment:

I certainly think that screening should be recommended. When I first presented with a breathing issue, probably related to my *****, my GP included PSA along with some other blood tests. At

	that stage it was *****, above the normal range but not much above for a ***** year old. ***** later it had risen to *****. This would suggest that the tumour was growing rapidly. If I had been tested annually, there would have been a history of probably lower readings, possible showing a slow upward trend. The first result of ***** would then have been a significant increase and I would probably have been referred then. That***** could have meant surgery ***** earlier and there is a very good chance that the tumour would not have had time to metastasise. My subsequent life would have been very different and I would have been far less a burden on the NHS. As a minimum I have ***** prosta injections, ***** blood tests, ***** oncology follow up appointments every year. If I could tolerate it I would have remained on the very expensive ARPI as well. In the future, I will probably look forward to Olaparib, scans, radiation, and maybe chemo. None would have been needed if I had been diagnosed just a little earlier. It has often been noted that an isolated PSA test is not a very reliable predictor of prostate cancer. That is true, but a history of PSA readings is a much better indicator of cancers that may require attention. I understand that some men will want any cancer to be cut out, but if they have a history of readings, it should lead to a much more informed discussion about their own risk, and they may be more willing to have active surveillance. Alternatives comment: At present, screening has not been recommended. However men over 50 do have a right to request a PSA test, and GPs should not use the screening recommendation as an excuse to refuse this. A public information campaign could encourage men who need to visit the toilet overnight to ask their GP for a test. Also the link between breast, ovarian and prostate cancers should be emphasised. A family history of any of these cancers should be a warning to men to get themselves tested.
P861	Affected Comment: I have received regular PSA testing since ***** due to strong family history (***** all with prostate cancer), and had confirmed Gleason ***** in *****. I remained on active surveillance until the MDT recommended treatment after a further biopsy confirmed significant changes in *****. *****. Evidence Comment: It is quite clear that I was high risk, but I had to continually take my own initiative to maintain the regular PSA testing which in due course led to MRI scans and 2 biopsies. I have definitely benefited from early diagnosis, and was quite content to remain on active surveillance until such time as further treatment was necessary. My story so far is a good one, and presents a model example of the benefits of early testing especially among high risk groups. I do not understand why this route has been viewed negatively and not positively. Discussion comment: I find it beyond belief that screening for those like myself who are high risk is not being recommended, and following that in due course the screening of all men of an appropriate age. Recommendation comment:

	Without question I believe that it should be recommended. At no point on my own journey do I think I have been unnecessarily tested or over treated. Whilst I do not look forward to my prostatectomy I know that it will save my life, as there is clear evidence of the progression of my cancer to the point where it could become life-threatening if left untreated. The combination of PSA, MRI and biopsy testing enables accurate diagnosis to be made and avoids over treatment, so there is no significant reason to delay offering an active screening programme at least to those who are high risk. Alternatives comment: Some men are anxious even at the thought of a PSA test, so clear and informed training to GP's is essential in this. Other comments: Please send a clear signal to all those who are in high risk groups to go immediately to their GP and request a PSA test as a starting point. The negativity around the screening programme is damaging to those who need to be encouraged to take action now.
P862	Affected Comment: I have Stage xxxx Prostate Cancer, which, were a screening programme been in place it may well have been much less serious and invasive. My cancer is incurable and has metastasized, so I'm on borrowed time even after ***** months chemotherapy, which in itself, is incredibly difficult to endure and recover from. A National screening programme would prevent advanced cancer such as mine and allow men to enjoy a better quality of life after diagnosis. Evidence Comment: No. From my viewpoint it's all about funding, but surely, early detection would, in the long run be more cost effective and enable men to carry on and continue to be productive members of society. Discussion comment: No. I just believe that they arrived at the incorrect conclusion based on overwhelming evidence. Recommendation comment: Yes, screening should be implemented at a pre- determined age and acted upon swiftly, should the results be positive for cancer. Alternatives comment: I don't think there is a viable alternative that won't be mired in delays and red tape, exactly what men do not need. Other comments:

	The Government needs to act and put a screening programme in place quickly. Not get bogged down in endless consultations, committee's or panels whilst men across the Country continue to be affected by this insidious disease. It beggars belief that this government is seemingly nonchalant about handing out over £15bn per annum for benefits to illegal immigrants, who've contributed absolutely nothing to the UK, whilst hardworking, tax paying people are being denied potentially life saving screening. It's disgraceful.
P863	Affected Comment: I am currently living with and being treated for advanced metastatic prostate cancer, which was officially diagnosed in *****. I have a significant family history of cancer. Notably, my sister passed away from metastatic cancer, and it was this specific family history that prompted me to request the initial PSA test that led to my diagnosis. I did not present with any symptoms. Evidence Comment: I noticed several key areas where important evidence was either excluded, missing, or limited by the data available: 1. The Stockholm3 Test was Excluded I noted that the Stockholm3 algorithm was entirely left out of the modelled screening pathway. It had been proposed as a second-line test (used after a PSA test) to help better identify which patients actually need an MRI. However, the necessary data was not publicly available. Due to confidentiality issues, restrictions on sharing modelling outcomes, and concerns over the quality and suitability of the data, the UK NSC and the SCHARR research team jointly agreed to exclude it from their evaluation. 2. The Cost of BRCA Gene Testing was Missed While the review found that screening men with known BRCA1/2 gene mutations is the most likely strategy to be cost-effective, I see that the economic model completely missed the **costs of the BRCA genetic testing itself. The model evaluated the costs of screening men who already know they are carriers, but it did not factor in the broader economic implications of rolling out genetic testing to identify these men in the first place. 3. Lack of UK-Specific Evidence for Black Men and Mixed Ethnicities I also found that the model lacked robust UK data regarding Black men. To estimate disease progression and cancer aggressiveness, the model had to rely on data from the United States. This is a significant limitation, as the US data may reflect delayed diagnosis due to healthcare access barriers rather than actual biological differences. Furthermore, men of mixed Black ethnicity were completely missed in this target group because the underlying Health Survey for

England (HSE) data grouped all people of mixed heritage into a single “any mixed race” category. 4. Unclear Data on Current PSA Testing Practices

Finally, I observed that there was no reliable evidence to show exactly how much opportunistic PSA testing is currently happening. The available data could not distinguish between a man receiving a PSA test because he requested it versus a man receiving one because he presented to his GP with symptoms. Because of this missing context, the model had to group them together, making it difficult to clearly define the “usual care” baseline against which the new screening pathways were compared.

Discussion comment:

Looking at the review’s discussions, conclusions, and draft recommendations, I have a few strong thoughts, particularly when comparing them to my own personal journey with prostate cancer: 1. The Recommendation Against Screening Men with a Family History

The UK NSC explicitly recommends *against* targeted screening for men with a family history of prostate, breast, or ovarian cancer, citing high uncertainty and the risk of over diagnosis. On a personal level, I find this difficult to accept. It was exactly my family history—specifically my sister passing away from metastatic cancer—that prompted me to ask my GP for a PSA test in the first place. That very test led to the discovery of my advanced metastatic prostate cancer (Gleason score *****) at age *****. If I hadn’t been tested based on my family risk, my cancer might have progressed even further before it was caught. 2. The Rejection of Whole-Population Screening Due to Treatment Harms

The committee’s draft recommendation is against whole-population screening because the PSA test is too unreliable and would lead to massive over diagnosis, subjecting men to treatments they don’t need. Having been through intensive treatment, I actually understand and validate this concern. I live daily with the severe side effects of dual hormone therapy (Zoladex and apalutamide/enzalutamide) and radiotherapy. I regularly experience intense fatigue, hot flushes, memory problems, sleep fragmentation, and bowel sensitivity. Given the physical and psychological toll these treatments take, I agree that putting men with slow-growing, harmless cancers through this would be devastating. 3. The Focus on BRCA1/2 Gene Carriers

I note that the only strategy the UK NSC is in favour of pursuing is targeted screening for men with confirmed BRCA1 and BRCA2 gene variants every 2 years, between ages 45 and 61. The data suggests these men develop faster-growing, more aggressive cancers, making screening more likely to do more good than harm. However, I think there is a significant gap in this recommendation: the economic model completely failed to account for the actual costs of rolling out the genetic testing required to identify who actually carries these BRCA mutations. Without a cost-effective pathway to identify these men, the recommendation feels incomplete. 4. Awaiting the TRANSFORM Trial

Finally, I strongly support the review’s conclusion to hold off on screening Black men until more data is gathered, specifically through the TRANSFORM trial. Since the current data is filled with uncertainties and relies heavily on US data that may not apply to the UK, utilising a trial that guarantees at least 10% representation of Black men and tests better diagnostic pathways (like MRI and genetic risk) seems like the most logical step forward.

Recommendation comment:

I believe prostate cancer screening should be recommended, but only in a highly targeted and risk-stratified way, rather than as a blanket policy for all men.

When looking at the evidence and comparing it to my own life, my stance is divided into a few key areas:

Why I agree with rejecting whole-population screening

I completely agree with the UK National Screening Committee's (UK NSC) conclusion to advise against screening the entire male population. The current PSA blood test is simply too unreliable and catches far too many slow-growing cancers that would never cause a man harm in his lifetime—a problem known as over diagnosis, which accounts for roughly 40% to 50% of screen-detected cases.

I know firsthand the severe physical and psychological toll of prostate cancer treatments. Because of my advanced disease, I have to undergo dual hormone therapy (Zoladex and Xtandi) alongside radiotherapy, which has left me managing profound fatigue, memory clouding, severe hot flushes, weight gain, sleep fragmentation, and bowel sensitivity. Other men face lifelong issues with urinary incontinence and erectile dysfunction after surgery or radiotherapy. Subjecting perfectly healthy men to these devastating side effects for harmless cancers would be doing much more harm than good.

Where I strongly disagree: Family History

The UK NSC explicitly recommends *against* screening men who have a family history of prostate, breast, or ovarian cancer, arguing that the strategy is highly uncertain and still leads to massive over diagnosis.

I strongly disagree with this based on my own survival. It was my family history—specifically my sister passing away from metastatic cancer—that prompted me to ask my GP for the PSA test in the first place. That proactive test is what led to the discovery of my advanced metastatic prostate cancer (Gleason score*****, *****) when I was *****. If a screening programme actively discouraged testing men with my risk profile, my aggressive cancer might have progressed significantly further before it was caught.

Where I agree with targeted screening: BRCA Carriers and Black Men

I fully support the committee's draft recommendation to pursue targeted screening for men with confirmed BRCA1 and BRCA2 gene variants every two years between ages 45 and 61. The data clearly shows these men develop faster-growing, more aggressive cancers, meaning early detection through screening is highly cost-effective and actually saves lives rather than just causing overdiagnosis.

As for screening Black men, who are at a higher risk of developing prostate cancer, I support the committee's decision to wait for better data. Right now, the economic models are filled with uncertainty because they have to rely on US data to estimate disease progression. I believe we should wait for the results of the upcoming UK-based TRANSFORM trial, which guarantees at least 10% representation of Black men and is testing better diagnostic pathways, like fast MRI scans, to find a more accurate way to screen than the flawed PSA test.

Alternatives comment:

I believe there are several crucial areas the NHS and the government should focus on to help people with prostate cancer, particularly by improving how we diagnose, monitor, and support patients through the realities of this disease. 1. Investing in Better Diagnostic Tools and Research

Instead of rolling out a blanket screening programme based on the flawed PSA blood test, the government should heavily fund and support innovative research like the TRANSFORM trial,. This large-scale UK trial is testing better diagnostic pathways, such as fast MRI scans and genetic testing, to find a more accurate way to detect life-threatening, aggressive cancers while reducing the overdiagnosis of harmless ones,. 2. Providing Holistic Support for Treatment Harms

From my own daily experience, the NHS could provide much better support for managing the severe, lifelong side effects of treatment,. Because of my hormone therapy and radiotherapy, I constantly battle profound fatigue, brain fog, and severe hot flushes that disrupt my sleep,. I had to independently find and use an ***** to manage my night sweats,. The NHS could formally integrate and subsidise management strategies for these physical and emotional tolls, including dedicated support for metabolic changes—like the pre diabetes, weight gain, and high blood pressure I have developed as a direct result of my cancer drugs. 3. Expanding Genetic Testing

The evidence clearly shows that men with BRCA1 and BRCA2 gene variants develop faster-growing, more aggressive prostate cancers,. However, many men do not know they carry these genetic mutations. The NHS could evaluate and fund better pathways for targeted genetic testing so we can proactively identify these high-risk men and offer them the tailored monitoring they actually need,. 4. Tackling Inequalities in Data and Care

The government must address the glaring gaps in our medical data regarding high-risk ethnicities. Right now, the UK has to rely on United States data to estimate how prostate cancer progresses in Black men,. Furthermore, men of mixed Black ethnicity are completely grouped into a broad “any mixed race” category in current UK health surveys, masking their specific risk profiles. The NHS must mandate and fund better representation of Black men and mixed ethnicities in clinical trials—a goal the new TRANSFORM trial is actively trying to achieve. 5. Improving Active Surveillance Protocols

Since over diagnosis is a massive issue—catching slow-growing cancers that would never cause harm in a man’s lifetime—the NHS could refine and better communicate its active surveillance pathways. This involves carefully monitoring the cancer with regular PSA tests and MRIs rather than immediately treating it. If the NHS can make this pathway more robust and psychologically reassuring for patients, we could spare thousands of men from the devastating urinary, bowel, and sexual side effects caused by unnecessary radical surgery or radiotherapy,,,.

Other comments:

Based on my ongoing journey with advanced prostate cancer, I have a few more specific recommendations for how the NHS and the government could improve the system, particularly regarding how long-term cancer care is managed: 1. Establish Integrated Cardio-Oncology and Metabolic Clinics

Since starting my dual hormone therapy (Zoladex and apalutamide/enzalutamide), I have developed *****. Currently, these side effects are managed somewhat separately by my GP, who put me on ***** and asked me to *****. I recommend that the NHS formally integrates cardiovascular and metabolic care directly into the oncology pathway. If we know these cancer drugs cause heart and blood sugar issues, proactive management should be a built-in part of the cancer treatment plan, rather than an afterthought for the GP to handle once the damage is already done. 2. Implement Proactive Bone Health Protection

Hormone therapy is notorious for causing bone thinning and osteoporosis. While my oncologist and I have discussed bone protection strategies like bisphosphonates, I was told that the usual practice is to wait until two years post-treatment to start osteoporosis medication, unless I

	specifically request it earlier. I already take Vitamin D3 and K2 supplements myself to help. Given the known risks, the NHS should automatically offer baseline DEXA scans and bone protection therapies from day one of hormone treatment, rather than waiting for bone health to deteriorate over two years. 3. Ensure Better Cross-Disciplinary Communication Cancer treatment doesn't happen in a vacuum; it impacts the whole body. For instance, the stress and physical toll of my diagnosis caused a severe flare-up of my *****. Later, I also had to explicitly ask my oncologist if it was safe to get a ***** because my treatment had caused my lymphocyte count (white blood cells) to drop, making me worry about infections. I recommend that the NHS implement better cross-disciplinary IT systems and care pathways so that a patient's GP, dentist, and dermatologist are fully synced with their oncology team. I shouldn't have to act as the middleman trying to figure out if my cancer treatment makes standard dental work dangerous. 4. Streamline Blood Testing and Logistics Living with this disease means my life is dictated by 12-week Zoladex injection cycles and quarterly oncology reviews. To ensure my doctor has the data they need, I often have to make separate trips to the hospital just to get my blood drawn a week before my appointment. The NHS could vastly improve the patient experience by allowing all routine oncology blood tests (like PSA and kidney function) to be done at local GP practices or community hubs with guaranteed instant data sharing to the hospital. Furthermore, making it easier to safely schedule treatments around life events—like when I needed a doctor's letter just to travel to Europe and Spain—would give patients like me a lot more freedom to actually live the lives we are fighting to save.
P864	Affected Comment: I have stage 4 prostate cancer Recommendation comment: As most men are asymptomatic they are usually at an advanced stage prior to detection. An effective screening programme is a must. Using the excuse of unnecessary treatment as an issue holds no relevance as an mri scan will be carried out before any other treatment. The fact that men have to be chemically castrated to live with this disease is reason enough for a screening programme to be forthcoming.

P865	Affected Comment: I among far too many others have this blood awful disease. If I had know about it earlier it well may not have affected me to the degree it has, along with the attendant side effects from surgery and radio therapy and, the on going blood tests and consultations with the oncologist and specialist nurses. How much does that cost the NHS? And that is just the financial aspect never mind the heart ache and mental stress for my family and I. For goodness sake open your eyes, wake up and take the long term view. Regular tests for men as for women and breast cancer. PLEASE. Let's have some common sense when considering prostate cancer. Recommendation comment: Simply from a financial point of view screening should be carried out regularly to catch the disease early, could save a lot of money and tears.
P866	Affected Comment: I was diagnosed in ***** with Advanced Metastatic Aggressive Prostate Cancer after I requested a PSA test at age ***** , with a PSA of *****. Evidence Comment: If I hadn't have requested a PSA test I wouldn't be here now as I showed no symptoms apart from unusual bowel movements. The first GP I saw refused my request and put me on *****. The 2nd GP I saw 2 weeks later (a male GP) sent me for a blood test which proved a very high PSA reading. Discussion comment: It seems that every decision is based on clinical evidence, and not by talking to affected men. Recommendation comment: Yes, I believe it should be recommend. After all, if women can have screening, why can't us men have it? Also in ***** my PSA started to slowly rise. As I am on ***** monthly blood tests I became increasingly concerned. An MRI scan showed an area of concern so I had a biopsy which confirmed the cancer had returned. My PSA level was *****. Alternatives comment: I think everything us men say about screening for prostate cancer will go by the way as statistics outweigh the real concern for us. Other comments:

	I'm sure if screening was put into practice the catching of PC early is better than not doing it. Ask the men, nothing beats having a scan or biopsy as leaving it is death.
P867	Affected Comment: Men with higher than average risk of contracting Prostate Cancer should be encouraged to request and be offered screening. To not do so will result in many men remaining undiagnosed until the cancer has become a life limiting or terminal condition. Recommendation comment: Yes as above
P868	Affected Comment: At ***** I was misdiagnosed with a benign prostate and it took some months to receive an advanced prostate cancer diagnoses. Discussion comment: I don't agree with it, I believe the lack of screening means that the whole area doesn't get the attention it should, from doctors or patients Recommendation comment: Yes to screening, reasons as above

P869	Affected Comment: My husband had no symptoms. Went to the Dr for a different problem. His PAA came back high. This was in *****, he then had to wait for a MRI scan, then wait for biopsies, the. Wait for a review. All this took until ***** when he was told he had locally advanced prostate cancer. He is now on hormone therapy for two year and is having radiotherapy. He has some many side effects already from the hormone therapy. If better screening was available and this was caught early he would have been given hormone therapy for ***** and no other treatment. Lives and quality of life depend on early detection Evidence Comment: Early detection is key to saving lives and giving me a good quality of life Quicker investigations -and results Discussion comment: As above Recommendation comment: 100% Early detection saves lives It also gives men a better quality of life. All the side effects of the medication are not nice and most have some This massively affects their mental health Detection. And prevention to progression are key Alternatives comment: Screening !!!!
P871	Affected Comment: My father died with prostate cancer (discovered post mortem). I was diagnosed in *****, Gleason *****, and opted for radiotherapy with androgen deprivation therapy. ADT will last for another *****. This has resulted in ED, mild incontinence, brain fog, general “menopausal” symptoms. I have lost muscle mass, and there is the potential for osteoporosis. Evidence Comment: It would help in the cost/benefit analysis to see comparative figures for breast cancer, and for screening for aortic aneurism.

	Discussion comment: Disappointing. Roll on TRANSFORM Recommendation comment: Yes. My cancer, which is at the more aggressive end, was only discovered because an alert GP ordered a PSA test (though I think she should have told me she was doing so). In the absence of that and a screening programme I would be blissfully moving towards Stage 4. Alternatives comment: Targetted information campaigns in deprived areas, together with targetting black men, and those with a family history. This is unsystematic, and many would fall through the cracks.
P872	Affected Comment: I was diagnosed with prostate cancer in *****. I was not experiencing any symptoms but my older brother was told that he had an enlarged prostate and he suggested that I should get checked out too. I was aged ***** at the time. He was told that his enlarged prostate was not due to cancer. I had a PSA test and the results were high, I then had a physical examination by my GP who thought I had a lump on one side of the prostate and referred me to hospital. I had a further physical examination at the hospital then an MRI scan and biopsies. Some of the samples taken showed an aggressive form of the cancer and I was offered the choice of a prostatectomy or radio therapy. After much thought and seeing a consultant surgeon and an oncologist I decided on the prostatectomy. This was a very worrying time for me and my partner (*****) and my daughter and grandchildren. Since my surgery I have had problems with incontinence and erectile dysfunction. Evidence Comment: Given that I had no symptoms and that if I hadn't had an older brother I wouldn't have had a PSA test I consider that I was lucky to get a diagnosis. If there was a screening service people like myself with no symptoms would be much more likely to be picked up. I think that counts as important evidence. Discussion comment: I understand that the PSA test is not always a very accurate test but without it my cancer might not have been picked up on and the following tests that I had after it are I understand are pretty accurate. Personally I would rather have the worry of a possibly inaccurate test than a lack of a positive diagnosis which in my case could have meant that there was no chance of any successful treatment. Recommendation comment:

	I think that screening should be recommended for the reasons given above and because prostate cancer is the most common cancer in men. Also women, quite rightly, have screening for breast cancer therefore why not for men and prostate cancer. Alternatives comment: I know that the PSA test can be inaccurate and I think more research could be funded into more accurate testing methods. I also think there could be more information put out to raise public awareness of prostate cancer.
P873	Affected Comment: I was diagnosed with prostate cancer in ***** aged *****. My ***** occurrences in the 1990's (*****) and the second led to his passing in *****. I have known of family history significance since then and have requested the PSA blood over the last ***** or more years and certainly annually over the last ***** years. It has provided not only a level of piece of mind but in a practical sense, the appropriate time to seek medical interventions. I considered myself reasonably fit and led a reasonably healthy lifestyle. I had absolutely no other signals or indicators other than the PSA result. The counselling in the NHS was tremendous and for the low level *****, they have guided me into a watching brief, albeit under the term of enhanced surveillance. I did not tell my children, wider family or general work colleagues of my condition for almost a year. When I did the clarity I was able to present and stability of the plan quickly allowed them to align and understand the situation, and we progress with ongoing life. The time I had adjusting to the early signal, really gave me time to think and put into place behaviours and actions that make the most of my health. The early clarity has provided the right balance and perspective such that, I have pro-actively lost weight to fall into a *****, amended my diet to be happy with virtually no meat or alcohol and undertaking far more exercise. The approach is also providing an example to the rest of the family and they now also follow similar pathways.

My male friends, all of similar age, are now all looking at the PSA testing – approx 60% were not up to then considering it. It has created a positive focus for many especially in contrast to friend of a friend (*****) from primary school days, who similarly had no symptoms, had a shoulder problem that has led to a stage 4 Prostate Cancer diagnosis and a completely different pathway.

I am so fortunate that, with knowledge and understanding, I pressed for the PSA test and was listened to by my local GP.

Evidence Comment:

I do think the evidence was somewhat 'aged' and did not perhaps have a fully balanced source such that it reflected the current understanding, the behaviours of men, their changing attitude to personal health and the wish to be well informed.

Discussion comment:

I like many people with PC attend groups for sufferers. These groups are very powerful to provide informed discussion and clarity of information on steps to move forward. Indeed I am among 5-6 people (~15%) in the local group who are in the 'watching' category, eager to learn and not wishing, or intending to jump to action.

I feel there is inadequate consideration of the perhaps 'softer' but nonetheless financially significant, positives.

A screening programme will also expand the knowledge and, importantly for men, raise the PC and health discussion into the mainstream.

At work I have raised the topic, and presented an internal video to make people aware. I've received overwhelming support for the conversation from both young and old. Those that are also having PSA tests are now openly engaging. It feels time to use the power of this screening to help make holistic improvements to men's health in general – and not just PC.

I really feel that this could be a pivotal change for men. I hope it is adopted.

Recommendation comment:

Yes it should be recommended.

It helps people who, like myself with no symptoms, learn and change and grow with the disease and it would allow those like my school acquaintance (*****) [no symptoms and Stage 4] have further options available to them.

The positive ripple effects beyond PC could also be huge – really grow men's health conversations for generations to come.

I also think that communication tools and the role of PC groups can also be used to create a better understanding of options and the way forward in mitigation of the potential impacts and, quite rightly concerns of workload, on the NHS.

Alternatives comment:

I can't see alternatives to new information without actually gathering the evidence but I can see a means of minimising the impact:

Local support groups do provide excellent communications, all from voluntary perspectives. There is the opportunity to ensure a fully balanced conversation via these support groups who provide balanced counsel for those living with / around the condition; they give of their time and support to make the most for those living with the disease. NHS support via resources for explanations, discussions, engagements with large relatively large numbers of patients. These groups support both the patient and their family. That's potentially quite a sizable population coverage in short periods of support. With these groups meeting after 'normal' work hours, could NHS roles have these hours recognised as part of their work scope?

Screening will probably show an increasing number of people with PC and if attending these support groups, will possibly provide an increasing proportion of 'watching' patients vs the numbers to those who have undergone surgery or therapies. If the concern is of an overwhelming of the NHS, perhaps there's a role here to help the conversations, maintain balanced perspectives, notwithstanding control of group dynamics and strong characters with polarising views.

Other comments:

We're stepping into the world of AI which needs to be fed with data – current data. And AI can handle the dynamics of more and more information. Embracing screening as a source of real and dynamic data, could bring forward opportunities of learning as the process unfurls. We've never had such an opportunity around the ability to look for trends in the disease, and find something new. Learn now, and we could possibly step back from the screening if we've collectively learned a different pathway.

Affected Comment:

My father was diagnosed in his early 60's prior to PSA availability and underwent radiotherapy. I had avoided testing as I dreaded the thought of cancer but due to family history I discussed getting a PSA with my GP and was tested in ***** at age *****.

I was physically fit (*****) asymptomatic and no co-morbidities. Initial PSA was *****. Follow up results were *****. I was referred to urology and the consultant reported a small prostate on DRE with right lobe firmness. Recommendation was mpMRI, calculate PSA density and biopsy dependant upon findings. MRI scan showed *****. Guided transperineal biopsy showed ***** cores with *****. Consultant indicated that this was a low volume, low grade cancer and likely slow growing. AS was recommended. I was surprisingly calm when told the news. The consultant mentioned that had I reacted badly, he would have suggested treatment at that point but we planned to monitor PSA, another MRI in 2 years and biopsy if thought necessary. *****. Due to increasing PSA the MRI was brought forward to ***** and apparently no change was seen but the volume estimate was changed to ***** which increased the PSA density to *****. PSA was ***** and I was advised to have a repeat biopsy. This was done in ***** and showed progression – *****. Following MDT review I was advised to consider treatment as this had progressed to a multifocal disease in all areas of the prostate but still contained within the capsule. This was unexpected after only ***** on AS but my priority was to avoid the possibility of the carcinoma breaking out of the capsule and affecting other areas with the potential of metastases. After much research I opted for surgery and had a RALP in *****. Histology revealed a *****. I recovered well and was able to do the *****. Of the potential side effects, my main concern was incontinence but this has not been a problem. Erectile function has progressively improved and I am essentially leading a normal life. Over the last 5 years my PSA has been undetectable. Had I not been tested I believe that the outcome could have been worse which would have made treatment more difficult and potentially life threatening. I didn't want to risk that, which was my choice, rather than relying on statistics. I have advised my son (*****) to get tested and other friends and family so at least they have a baseline PSA level. If they are symptomatic, this is extremely important. I am aware of some friends on AS that have had sudden changes in their PSA resulting in the need for treatment and also subsequent follow up treatment.

Evidence Comment:

In the UKNSC review of Oct 2020, the comments submitted by Prostate Cancer UK and CHAPS Charity; TACKLE Prostate Cancer; ORCHID sum up the situation well. Not only in 2020 but also today.

Discussion comment:

I get very frustrated with the comments about the PSA test not being accurate. The term accuracy refers to a test result being correct or not correct when compared to a designated reference method. Manufacturers of the test go to great lengths to ensure that a test is not only accurate but also precise so that repeated measurements of a sample will yield results that fall within acceptable parameters. The PSA test is accurate, however, it is not specific for Prostate Cancer although it is specific for conditions that relate to the prostate gland in men and it is in this context that it should be viewed.

This is no different to blood tests that are done to assess the function of other organs or metabolic processes in the body such as Renal, Liver, Bone and Thyroid profiles.

As PSA is specific to the prostate, should the result be abnormal according to reference range studies done on populations deemed to be 'healthy', this is a trigger for further investigation in the same way as other tests. The trigger point should be based upon the expected values which with PSA will depend upon age in men as the prostate may get larger with age. However, if a man should have symptoms such as LUTS, infection or bleeding these need investigation. With regard to False Positive results, there needs to be an investigation as to the cause of a raised result. A large prostate, prostatitis and urinary issues not related to cancer may raise the result. These reflect an issue so are not false positives. Even today, men are not necessarily given advice about refraining from activities such as heavy exercise and sexual activity prior to having a PSA test may cause a raised level. These would be false positives. They may find out by talking to other men or by reading. Even a poorly informed GP may not mention it. Without any other obvious cause a MRI would help clarify the situation. With regard to Overdiagnosis, should a biopsy be recommended and cancer discovered, this may not develop further depending upon the Grade Group. However this is unknown or not guaranteed in individual cases. Any effects of biopsy, although subjective but potentially unpleasant, are likely to be temporary. Men should be given non-biased informed guidance so that they may decide their best course of action. Most men are asymptomatic and AS would be the recommended action. In the majority of cases, with appropriate mental support if necessary, they would be able to live a relatively normal life as they will not be troubled by side effects of treatment. They could take advantage of the vast amount of research into better markers, diagnosis and treatment options should they have to make a choice in future. The key point is that they are aware of their circumstances early rather than finding out at a later date that they require urgent, unpleasant, treatment or that it is in fact too late.

Recommendation comment:

Currently, I think that men, regardless of ethnicity, with a family history of PCa, genetic pre-disposition (family history of breast, ovarian cancer etc.) should be invited for a PSA test from the age of 45 onwards. If they are symptomatic there should not be an age limit.

There should not be any barrier to men obtaining a test from age 50 as per guidelines. Even today some GP's dismiss requests for a test and I advise anyone who should mention this in a group that I host to change GP's if necessary. Any counselling given should be non-biased and the pros and cons should be clearly set out. Even if this is not a formal screening process like for bowel cancer, there should be adequate publicity encouraging take up of the PSA test (or whatever may supersede it in future) and reassurance to reduce any taboos or embarrassment that may mitigate against it. It is a simple blood test. If better markers or combination of these with PSA are found (such as liquid biopsies, ultrasound, rapid MRI) that can improve diagnosis or reduce the need for biopsies these should be used.

Alternatives comment:

Even today, many men do not know that they have a prostate gland, where it is or any idea what it does. All the prostate cancer charities produce information sheets, webinars, videos and provide other services, such as the Specialist Nurses at Prostate Cancer UK, to help educate men understand their bodies and what to do if they think they may have an issue. These should be sponsored by government and publicised via the NHS app and Social Media. The important thing is that men are better equipped to seek assistance and any issues are detected early.

P875

Affected Comment:

I was diagnosed with Prostate Cancer when I visited my GP with an unrelated health matter in *****. I had no symptoms or family history of prostate cancer

Had I not have visited my GP on that fateful day in ***** it is quite likely that I would not be here today

Evidence Comment:

So many press items talk about symptoms but once symptoms are evident curative treatment can be very difficult.

Talk of the presence of the Braca faulty gene is fine but who knows if they have the faulty gene? Does this mean there has to be a survey to determine who has this gene?

Currently men of black afro caribbean origins have an even higher incidence of Prostate Cancer than white anglo-saxons

Recommendation comment:

Given the incidence of PCa in men, some sort of monitoring screening should be implemented so that early intervention can be achieved giving a better chance of curative treatments

Alternatives comment:

What other alternatives would be considered, within the group to which I belong many of us were diagnosed with no symptoms.

Other comments:

Raising the profile of awareness of this disease needs to be achieved so that men can be proactive and demand an initial PSA check

Affected Comment:

Yes, I am a *****-year survivor of advanced prostate cancer (*****).

My wife is my supportive partner in this journey with the disease.

Evidence Comment:

On reading the NSC report, it would appear that the following evidence was not taken into consideration in reaching your conclusion.

Hear Me Now 1 – 2013

Hear Me Now 1 year on – 2015

Dr Rose Thompson

Cancer Information Specialist Advisor

The above papers are seen as impactful reports in response to evidence showing that black men were twice as likely to die from prostate cancer in the UK. These reports shed light on the uncomfortable reality of prostate cancer in Afro-Caribbean black men.

The report 'Hear Me Now 1' was launched in the Houses of Parliament in 2013 and presented crucial recommendations to confront this inequality.

European Randomised Study of Screening for Prostate Cancer (ERSPC).

Data showed at follow-up after 23 years, prostate cancer mortality was 13% lower in the screening group vs the non-screening group.

Discussion comment:

I argue the NSC has got it wrong, following their 2025/2026 decision not to recommend national screening for most men based on the following: 1. Failure to Address High-Risk Groups (An inequality Issue)

By neglecting Black Men, we in the black community I argue that by not recommending a targeted programme for Black men (who are twice as likely to die from prostate cancer), the NSC is deepening health inequalities, as highlighted in both of the 'Hear Me Now' reports.

Not taking account of Family History: The decision not to immediately offer screening to men with a family history of the disease, I see as a major oversight, which leaves high-risk individuals vulnerable.

In a recent article, over 120 Members of Parliament warned that the current "opportunistic" testing system (where men must ask their GP) is unfair, as it misses men in deprived areas who are less likely to seek, or get, help. 1. Outdated Evidence and Modelling

Underestimating Modern Diagnostic Advances: I contend that the NSC's modelling does not reflect current practice, which now includes improved MRI scans and better, safer biopsy techniques.

Misjudging Overdiagnosis Risks: Reports suggest the NSC's model overstated the risks of overdiagnosis (treating harmless cancers) and underestimated the benefits of early detection, with campaigners arguing that diagnostic harms have fallen by 79%.

"Waiting for Perfect Data": Since my diagnosis in *****, I have constantly heard that blackmen are at a 1:4 risk. Current data is showing that this still applies. The 'Hear me now (2013)' report referred to the poor NHS ethnicity data collection. How can you assure the black community that the TRANSFORM results due in (2027) will show any improvement in the data collection, referencing black men to support their inclusion in a national screening programme? 1. Over-reliance on "Unreliable" Test Data

While the NSC maintains that the Prostate-Specific Antigen (PSA) test is unreliable, this is the only test that we have right now. However, as someone who has the disease and is an advocate for those with this condition, over the years, I have kept myself informed of developments and am aware that there are improved diagnostic pathways for prostate cancer. Surely, this then means that the PSA is the first step and, supported by other diagnostic tools, will provide a more accurate diagnosis.

With reference to the BRCA gene mutations point, whilst I understand the high incidence of these individuals developing prostate cancer and agree with their inclusion, I query the following:-

How many people know they have this gene?

What is the cost of testing individuals to identify the gene?

Recommendation comment:

Writing as a black male diagnosed ***** years ago with this disease, I have seen many friends and colleagues succumb to it. I believe strongly that blackmen should be identified as a 'high-risk' group and be included in the recommendations I have stated. I would also suggest that those with a family history of prostate/breast cancer, and men in deprived communities, be included as 'high-risk groups' and be offered screening.

Waiting for the results of the TRANSFORM trial in 2027 makes me concerned that we will be no further forward, with the ethnicity data breakdown for an informed decision to be made regarding the inclusion of blackmen as a high-risk group for inclusion in the screening program.

This is particularly so if the number of blackmen recruited to this trial is seen as 'statistically insufficient' to draw any conclusions.

Alternatives comment:

GP health practices should proactively identify men within a certain age group to do opportunistic health screening for prostate cancer.

Other comments:

NO

P877	Affected Comment: I was diagnosed with Prostate Cancer in ***** by chance. If I had been part of a screening programme this would have been picked up far earlier Discussion comment: I believe that the decision not to have a proper screening programme is cost based not health based so there are many people who will die that could be saved. Recommendation comment: Screening should definitely be recommended. There are real people behind every model. Real families. Real funerals. Real grandchildren who grew up without someone. How many QALYs did you assign to a man who dies at 67 because he wasn't screened? Alternatives comment: Screening is the obvious way forward. Maybe in the future a self test can be developed however before then screening would seem to be the way forward, Breast, cervical screening takes place so prostate? Other comments: Please..... just please, get screening done.
P878	Affected Comment: I was diagnosed with prostate cancer and had my prostate removed by robotic surgery Evidence Comment: Having experienced poor care and responses from my original consultant, and having to change health authority to get the treatment I believed I required, I think more emphasis should be place on the evidence/experience of patients. Some Consultants and medical professionals have an incorrect belief that they know everything and are always right. Discussion comment: See the previous answer Recommendation comment: Screening should be recommended for everyone that wants it, but not initially offered to everyone. I had symptoms and fears of prostate cancer due to 3 members of my close family having cancer.(including 2 deaths due to cancer). My doctor initially refused to do a PSA test until I went to a charity testing event, when a high PSA reading prompted the charity to write to him, and I was then referred to a consultant that eventually led to my operation.

	Alternatives comment: No. keep the screening programme but only test those that want it. The majority will ignore the risks or decide to live with any symptoms rather than face treatment. Other comments: Listen to patients' experiences
P879	Affected Comment: My friend has received a terminal diagnosis at *****. Screening would have saved his life. Recommendation comment: Screening must happen to save many lives for a simple test. Cervical screening has done this for women.

Affected Comment:

Yes, I was diagnosed with Stage IIIA Gleason 9 (4+5) PCa at age ***** purely as a result of asking my doctor to do a full blood test including PSA as a healthy man check – I had no symptoms. He noted a high PSA (*****) and offered another blood test ***** months later. At that time the PSA had grown to *****. He referred me to a urologist, who conducted a rectal exam, which led to an MRI and then a biopsy. I was then offered different treatment paths from watch and wait for symptoms, through brachytherapy or EBR to RP. I selected RP. A decision was made later to follow up with EBR. My PSA never hit zero and has been growing since (*****). I am likely to survive at least ***** , despite G9, Stage III at diagnosis and BCR since. Most likely, my survival so far is due to early diagnosis. This was while I was living in ***** – somewhere that I think we in the UK could learn from.

Evidence Comment:

1) The study does not seem to take account of the cost to the healthcare system of treatment and care for those who progress to metastasis and then death, that could have been avoided. The focus is on QALY's and the cost analysis seems to be a simple cost of screening and treatment.

Discussion comment:

1) Mischaracterising the number of lives saved, as “small”.

In the infographic and in Section 2.3 of the narrative, reference is made to studies evaluating risk reduction from screening. The results are that deaths could be reduced by between 0.09% and 0.22%. These are multiplied by 1,000 in order to show that they produce a “small number.” But the relevant base is the male population between 50/55 and 69/74yro. In the UK, this is over 5,500,000. $0.22\% \times 5.5m = 12,100$ men's lives that probably could be saved by screening. The 0.22% comes from a European study with a 23yr review period. If we divide 12,100 by 23, we get 526 each year. By comparison, the number of knife deaths in the year ended March 2024 in England and Wales was 262 (ref House of Commons Library). The total homicides was 570. Imagine if the Home Secretary, said this was a small number and not worth spending the resources to reduce it. The number of lives potentially saved is NOT SMALL.

2) Conflating the harms of screening with harms from treatment.

The narrative conflates harms from screening and harms from treatment. For example, on p.4 of the narrative, the first paragraph opens with the sentence “There are also several harms associated with screening. That same paragraph then seamlessly moves into a detailed description of harms from treatment. These are different processes, with widely differing scales of harm. Screening involves blood test, MRI and then biopsy only in the case of a positive MRI scan, at which point the MRI will have identified a suspicious development in the organ, even if it does not finally get labelled as prostate cancer. Even then, the harms from biopsy do NOT involve incontinence or erectile dysfunction. Section 4.7.1 explains that the model uses treatment-related side effects, and a vague reference to the emotional impact of a cancer diagnosis. It is not clear that, or how, the modelling disentangles harms of screening from harms of treatment, leading to the conclusion that the two are conflated. The harms from screening are not transparently evaluated in the modelling.

3) Misrepresenting the clarity of analysis that gives a result of net negative impact

In the modelling narrative p.18, incremental net monetary benefit is identified as the primary health economic outcome used for the study. Figure 21 on p.96 shows a clear positive NMB for screening between the ages of 55 and 60. p.98 indicates an 80% probability that NMB is positive in these age groups. However, applying the Green Book scenarios allows for adjustment in extraneous economic factors that are hypothetical at the very least (including the discount rate, which is a topic of endless debate by economists). These factors can be manipulated to deliver negative outcomes. The document clearly shows a net positive impact for screening in certain age groups, while at the same time highlighting the scenario-based uncertainty inherent in the modelling

Recommendation comment:

Yes, for those in the age bracket identified with positive NMB between c.58 and 60yr old.

At the same time, the screening process appears to be broken and that requires significant investment in processes and training. The path from PSA through MRI and then biopsy should not lead to as much so-called over diagnosis as seems to be the case. For example, a single PSA does not indicate velocity and we all know that it might mis-indicate cancer. At least two if not more PSA should be taken to show consistently high readings and also growth.

Alternatives comment:

Avoiding screening is a fool's errand. Across all cancers, early detection is the best path to avoiding untimely death and future healthcare costs. Only through screening, when the process is effective, can serious and life-threatening cancers be distinguished from benign and non-life-threatening.

Other comments:

Get serious about fixing the process and training of doctors and pathologists to make screening effective.

Get serious about early diagnosis, effective screening.

Shift the attitude in healthcare policy towards keeping people out of hospital and healthy, so as to minimise the social and economic burden of managing long term health issues

Affected Comment:

In December *****, at age *****, I was diagnosed with an aggressive Gleason ***** (Grade Group 3) prostate cancer. I was entirely asymptomatic. My diagnosis was only possible because of an “opportunistic” PSA test and the modern “optimum pathway” of mpMRI and targeted biopsy. I subsequently underwent a radical prostatectomy.

Today, in February 2026, I am navigating a biochemical recurrence with a rising PSA currently between ***** ng/mL. While a recurrence is never the desired outcome, my initial detection via screening has fundamentally changed my prognosis from “terminal” to “manageable.”

The Clinical Reality of the “Salvage Window”

The UK NSC's draft recommendation expresses concern over the “harms” of screening. As a patient, I argue that the greatest harm is being denied the “salvage window.” Because my cancer was caught early in *****, my recurrence in ***** has been detected at an ultra-low level. This allows me to access salvage radiotherapy or focal treatments (such as those validated in the February 2026 UCLA/Imperial trials) with curative intent. Had I waited for symptoms to appear—the default under a non-screening regime—I would likely have been diagnosed with metastatic disease in*****. In that scenario, I would not be “in the game” for a cure today; I would be facing palliative androgen deprivation therapy (ADT).

The Failure of the “Anxiety” Argument

The Committee's discussion frequently cites “patient anxiety” as a reason to avoid screening. I find this paternalistic. The anxiety of a diagnostic pathway is a clinical hurdle; the anxiety of being told you have incurable stage 4 cancer because the system waited for you to “show symptoms” is a life-shattering trauma. My current anxiety regarding my ***** PSA is mitigated by the knowledge that I have treatment options—options that only exist because I was screened.

A Direct Challenge to the BRCA-Only Model

I am not a BRCA carrier. Under the proposed draft recommendation, I would not have been screened. Yet, I had a Gleason ***** cancer—a volume of disease that is undeniably aggressive and lethal if left unchecked. By limiting screening to genetic carriers, the NSC is knowingly abandoning thousands of men who, like me, harbour aggressive “wild-type” cancers that are perfectly detectable and treatable if caught early.

Conclusion

The 2026 National Cancer Plan aims for 75% of cancers to be diagnosed at Stage 1 or 2. You cannot achieve this for the UK's most common male cancer by waiting for symptoms. Screening gave me a five-year lead time and a “second chance” at a cure via salvage therapy. I am asking the Committee to ensure that every man in the UK is afforded that same “buffer” of time. My survival should not be a matter of luck or personal initiative; it should be the standard of care.

Evidence Comment: 1. The 23-Year ERSPC Follow-Up Data (Published Oct/Nov 2025)

The Committee's review may rely on older 16-year data from the European Randomized Study of Screening for Prostate Cancer (ERSPC). Important new evidence from the 23-year follow-up (published in the New England Journal of Medicine, Oct 2025) shows that the benefit-to-harm ratio has improved significantly. The “number needed to treat” to save one life has fallen from 18 to 12. This brings the effectiveness of prostate screening in line with established programmes for

breast and bowel cancer. The NSC must incorporate this longitudinal evidence which shows that the life-saving benefits of screening continue to grow over time. 1. The 79% Reduction in Diagnostic Harms

The draft recommendation heavily weights the “harms” of biopsy and overdiagnosis. However, it appears to undervalue evidence from the last five years showing that the mpMRI-led pathway has reduced diagnostic harms (such as unnecessary biopsies and infections) by up to 79% in NHS practice. By using the MRI as a gatekeeper, we no longer “over-biopsy” men with low-risk disease. My own case (Gleason ***** is evidence that this pathway successfully filters aggressive disease from indolent cases, yet the NSC’s harm-modelling still seems anchored in the “pre-MRI” era of 2018 and earlier. 1. Results from the PRIME and PACIFIC Trials (2025)

The Committee cites the “cost and complexity” of MRI as a barrier to a national programme. The NSC should consider evidence from the PRIME trial (published in JAMA, 2025), which proves that faster, cheaper biparametric MRI (bpMRI)—which skips the contrast dye injection—is just as accurate as the standard mpMRI. This significantly lowers the cost and resource burden on the NHS, making a targeted screening programme far more feasible than the NSC’s current economic models suggest. 1. Widening Inequality Data (National Prostate Cancer Audit 2025)

The 2025 National Prostate Cancer Audit (NPCA) reports that health inequalities in prostate cancer outcomes are widening, not narrowing. By not recommending a formal screening programme, the NSC is effectively endorsing the “postcode lottery” of opportunistic testing. The evidence shows that Black men and those with a family history are being diagnosed with advanced disease at higher rates because we lack a structured, proactive invitation system. 1. Clinical Evidence for the “Salvage Window”

The review focuses heavily on initial diagnosis but misses the evidence regarding the salvage treatment window. As a patient currently navigating biochemical recurrence (PSA *****), my early diagnosis (at age *****) provided a window for curative surgery and has now afforded me a “second chance” for salvage radiotherapy. This multi-stage safety net is only possible with early detection. The NSC must consider the quality-of-life and survival benefits of being able to access salvage therapy, which is impossible if a patient is first diagnosed at a metastatic stage.

Discussion comment:

I strongly disagree with the recommendation to limit targeted screening solely to BRCA carriers. While a step forward, the conclusion that the “harms outweigh the benefits” for a wider risk-stratified programme is based on an outdated diagnostic paradigm. 1. The “MRI Gatekeeper” Negates the Overdiagnosis Argument

The discussion relies heavily on the risk of overdiagnosis and overtreatment. However, my clinical experience mirrors modern evidence (e.g., the PRECISION trial) which proves that the multi-parametric MRI (mpMRI) pathway acts as a sophisticated gatekeeper. In ***** , at age ***** , this pathway successfully distinguished my aggressive Gleason ***** cancer from indolent disease. The NSC’s conclusion fails to fully weight the fact that the modern MRI-first pathway reduces unnecessary biopsies by up to 40% and virtually eliminates the diagnosis of insignificant cancers. To base a 2026 recommendation on “harms” from the pre-MRI era is a clinical anachronism. 2. The Clinical Necessity of Detecting Gleason 4+3 (Grade Group 3)

The draft discussion implies that many screen-detected cancers are “harmless.” A Gleason 4+3 diagnosis is fundamentally NOT harmless; it is a high-volume, aggressive disease. Without my opportunistic PSA test, I would have remained asymptomatic until my cancer was metastatic and incurable. The NSC’s recommendation effectively accepts that men with curable,

aggressive disease should wait for symptoms—at which point the window for curative surgery has often closed. 3. Ignoring the “Salvage Window” in the Benefit Analysis

A critical omission in the NSC’s conclusion is the value of the “salvage window.” I am currently navigating a biochemical recurrence (PSA *****). Because I was diagnosed and treated early, I am in a position to utilize salvage radiotherapy or other curative-intent therapies. This “second chance” at life is a direct benefit of early screening. If I had been diagnosed late, my only option would be life-long palliative androgen deprivation therapy (ADT). The NSC must include the survival and quality-of-life benefits of access to salvage pathways in their final modelling. 4. The Fallacy of “Anxiety” vs. Terminal Reality

The recommendation prioritizes the “harm” of procedural anxiety over the “harm” of a terminal diagnosis. As a patient, I can confirm that the anxiety of a diagnostic pathway is a manageable, clinical hurdle. The anxiety of a metastatic diagnosis, caused by a lack of screening, is a catastrophic life event. The Committee’s moral weighting of these two “harms” is profoundly out of step with patient values.

Conclusion:

The NSC must shift from a “BRCA-only” model to a risk-stratified programme that includes men based on age (up to 75 for surgical candidates), ethnicity, and family history. We have the tools (PSA + MRI) to do this safely now.

Recommendation comment:

Screening should be recommended, but the current draft proposal is far too restrictive. The UK NSC should expand its recommendation beyond BRCA carriers to a risk-stratified programme for all men over 50 (and from 45 for Black men and those with a family history), but should continue to provide PSA testing on personal request.

My reasons are based on both the latest longitudinal data and my direct clinical experience: 1. The 23-Year Evidence Shift

The Committee’s concerns about “harm vs. benefit” are increasingly decoupled from modern data. The 23-year follow-up of the ERSPC trial (published late 2025) shows the “number needed to treat” to save one life has fallen to 12. This brings prostate screening in line with—or ahead of—other national programmes. The NSC’s draft fails to fully weight this long-term mortality benefit. 2. Modern Diagnostics Have Reduced Harms by 79%

The draft recommendation cites “overdiagnosis” and “procedural harm” as barriers. However, recent analysis (2025/2026) shows that the mpMRI-led pathway has reduced diagnostic harms by 79% compared to the older “biopsy-all” methods. At age *****, the MRI acted as a successful gatekeeper for me, identifying a Gleason 4+3 (Grade Group 3) cancer while filtering out insignificant disease. The NSC must judge screening based on 2026 diagnostic precision, not 20th-century complications. 3. The Life-Saving Value of the “Salvage Window”

The most overlooked benefit of screening is the creation of a “salvage window.” I am currently navigating a biochemical recurrence with a PSA of *****. Because my cancer was caught early via an opportunistic PSA test, I am still “in the game” for curative-intent salvage therapies (such as the focal salvage treatments validated in the Feb 2026 Imperial College studies). If I had waited for symptoms, I would likely have been diagnosed with metastatic disease, where “salvage” is no longer an option. A screening programme doesn’t just provide an initial cure; it

provides a lifetime of manageable monitoring. 4. Ending the “Postcode Lottery” of Opportunistic Testing

The current recommendation against wider screening effectively endorses a “postcode lottery.” My survival was dependent on my own initiative. This creates deep health inequalities, particularly for men in lower-income areas or those who do not have a “pushy” relationship with their GP. A formal invitation-led programme is the only way to ensure equity of access.

Conclusion: The NSC must not wait for the full results of the TRANSFORM trial in several years’ time while 12,000 men continue to die annually. The evidence from the MRI-first pathway and the 23-year ERSPC follow-up is already sufficient to support a targeted, risk-based programme now.

Alternatives comment:

While the 2026 National Cancer Plan and the 28-day Faster Diagnosis Standard are welcome improvements, they remain reactive. They help men once they are in the system, but they do nothing for the asymptomatic thousands who remain “unfound.” The NHS and Government should consider the following proactive alternatives to support better outcomes: 1. Mandated Proactive ‘Case Finding’ in Primary Care

Instead of a full screening invitation bureau, the NHS could implement a mandated ‘Proactive Case Finding’ protocol. GPs should be supported with automated digital flags to offer a PSA test to every man in a high-risk category (those over 50, Black men over 45, or those with a family history) during any routine appointment. This would bridge the gap between “opportunistic” testing and a formal programme, ending the current postcode lottery where survival depends on a man’s personal initiative or his GP’s individual stance. 2. National Rollout of ‘One-Stop’ RAPID Clinics

The NHS should fast-track the nationwide rollout of the RAPID (Rapid Access to Prostate Imaging and Diagnosis) model. My own success in catching a Gleason 4+3 cancer was due to the “optimum pathway” of mpMRI and targeted biopsy. A “one-stop” clinic where MRI and biopsy occur on the same day—or within a week—dramatically reduces the “worry time” and psychological harm the NSC cites as a barrier to screening. 3. Investment in High-Sensitivity Diagnostics for Recurrence

For men like myself navigating biochemical recurrence (PSA *****), there is currently a “diagnostic gap.” We often have to wait for the cancer to grow until it is visible on older scans. The Government must increase investment in PSMA-PET imaging and high-sensitivity “liquid biopsies” (which can return results two weeks faster than conventional tests). Helping people with the condition means ensuring that “salvage” treatment is timed perfectly, not just waiting for a metastatic crisis. 4. Home-Based PSA Monitoring and ‘Virtual’ Care

I support the 2026 Cancer Plan’s commitment to home-based PSA testing. This should be expanded to all men on active surveillance or post-treatment monitoring. Empowering men to monitor their PSA from home reduces the clinical burden on the NHS and allows patients to manage their “anxiety” in a familiar environment, rather than a hospital waiting room. 5. Standardized Access to Clinical Nurse Specialists (CNS)

Every man, from the moment of a raised PSA, should have access to a dedicated CNS. Managing the transition from a primary diagnosis to the monitoring of a recurrence requires specialized psychological and clinical support that is currently inconsistently provided across the UK.

Conclusion: These measures would significantly improve the lives of men already diagnosed. However, they are secondary to the primary need for a screening programme. We cannot “optimise the pathway” for men who never get to the front door because they were never invited to take a simple blood test.

Other comments:

I offer the following four strategic recommendations to modernize the prostate cancer pathway and address the current “dead zone” in diagnostic equity: 1. Standardize PSMA-PET for Early Recurrence (PSA >0.1)

Current NSC modelling focuses on initial diagnosis, but it overlooks the management of the 20–30% of men who experience biochemical recurrence. I recommend that PSMA-PET imaging be standardized for men with a rising PSA as low as ***** ng/mL, rather than the traditional 0.5 threshold. As highlighted in the February 2026 research (JNCCN), early imaging at these ultra-low levels allows for “precision salvage” therapy, significantly improving progression-free survival. The NSC must recognize that a screening programme is only as good as the recurrence-monitoring system that follows it. 2. Integrate AI-Assisted MRI Interpretation (2026 Pilot Model)

The NSC cites “radiologist capacity” as a primary cost barrier. I recommend the national adoption of AI tools (such as the Lucida Medical “Pi” tool currently being trialled in 15 NHS hospitals as of early 2026). These tools can interpret MRI scans in minutes with 95% accuracy, acting as a high-speed triage to identify high-risk lesions. This would allow the NHS to scale a targeted screening programme without a corresponding linear increase in human radiologist hours, negating the “resource harm” cited in the draft review. 3. Accelerate “Home PSA Testing” as a Screening Triage

The 2026 National Men’s Health Strategy promises home PSA testing for monitoring by 2027. I recommend this be accelerated and used as a “Stage 0” triage for a national screening programme. By allowing men to perform a finger-prick test at home, the NHS can overcome the primary barrier of “GP friction.” Only those with an elevated home result would enter the clinical pathway for an MRI, dramatically reducing the burden on primary care. 4. Establish “Men’s Health Champions” in Primary Care

Data from Healthwatch (Oct 2025) indicates that 79% of men would attend screening if invited, yet 60% have never requested a test. I recommend the creation of “Men’s Health Champions” within Primary Care Networks. Their role would be to proactively reach out to high-risk cohorts (Black men and those with a family history) to offer the “Informed Choice” consultation. This moves the burden of “initiative” away from the patient and onto the system, directly tackling the health inequalities that the current “opportunistic” model exacerbates.

Closing Thought:

The NSC must stop viewing prostate cancer through the lens of 2018 data. With AI-led triage, home-based testing, and high-sensitivity PSMA imaging for recurrence, the “harms” of the past have been largely mitigated. It is time for the UK to join its European peers in offering men a proactive, risk-based pathway.

P882	Affected Comment: I had problems passing water first thing in the morning, while working in the care industry, I was aware it would benefit me to see my GP after a conversation and a digit test and a PSA blood test which only showed a count of ***** my GP advised an MRI scan result a shadow on my prostate, after consultation at ***** hospital, I was informed I had cancer although confined to my prostate, I Was given options and decided, on robotic operation to remove, on biopsy the growth had spread. There was ***** months between diagnosis and operation. Any longer it would of spread outside the prostate. As my count was only ***** and I had decided just to monitor the situation, my situation would of deteriorated. I seriously believe screening would of found this I was aged ***** at diagnosis. Amazing surgeon love NHS Evidence Comment: By reassessment estimated every 3 years by the uk NSC to recommend whether population screening for over 100 conditions should be introduced modified or stopped based on safety and cost effectiveness is not best practice.. Discussion comment: It is said PAS testing but I think it is a starting point my MRA test was proof Recommendation comment: Should be something. There are approximately 293,000 males in receiving long term care in England They may not be aware they have a problem Alternatives comment: Is it possible to issue GP s practice s with a scanner to monitor enlarged prostate s as a starting point, Other comments: Maybe start with giving the GP practice s more help in this area
P883	Affected Comment: Yes both family and friends. Makes no sense NOT screening surely saves money with early detection and treating less progressive cancer. Men should have equal screening that that of our cervical and breast screening. Recommendation comment: Yes, see above.

	Alternatives comment: Many alternatives ???!! Watchful waiting for a friend has not been the safest choice. Other comments: To act as swiftly as possible to ensure lives more are saved !
P884	Affected Comment: My husband has had his prostate removed after stage 7 cancer on the gleeson scale was discovered, by chance, after he was admitted to hospital for gallstones. Discussion comment: I feel that screening should be routinely offered, particularly for young men and where there is family history. Recommendation comment: Should be for reasons given above. Alternatives comment: More awareness, encouraging men to look after their health through advertising.
P885	Affected Comment: I have prostate cancer diagnosed ***** years ago If screening had been in place would have caught earlier. Hopefully early enough not to be stage 4 Prostate cancer needs a proper screening programme supported by the UK Government Evidence Comment: The evidence considered by the UK NSC,was outdated and showed little understanding of the advances made in detection and treatment. The whole report was very disappointing and seemed to be 20 years out of date. The progression made was not reflected in the report by the UK NSC,. Discussion comment: Very poor conclusion and how do you find the people recommended for treatment in the report. Recommendation comment: Screening must be recommended to reduce the number of deaths by this terrible illness

	Alternatives comment: Screening programme is the best option. Education may help and more positive responses from GP'S in responses to requests for Screening. Other comments: Just get a screening programme in place that checks all men over 50.
P886	Affected Comment: Personal ; Asymptomatic in ***** Aged *****- PSA and Rectal examination in a mass screening clinic with *****. PSA ***** and DRE exam acceptable: Asymptomatic in ***** another ***** mass screening as ***** ; PSA***** and DRE exam suspicious; MRI revealed evidence of prostate cancer, confirmed by Biopsy. Treated with curative Radiotherapy and on going Hormone Treatment. Family affected knowing I had cancer. Raised need for friends to be tested; General : As a ***** and ***** where ***** have been examined by ***** I have supported men who have been diagnosed and undergoing treatment. Also personally know others from my circle of ***** who have been late diagnosed at *****. had stage 4 Prostate and died within two years, others who have had prostate removed, and others diagnosed and receiving treatment. Evidence Comment: My experience has been through arranging screening clinics with ***** , who volunteers her time freely to screen using PSA Blood and Digital Rectal Examination rather than just PSA. None of the evidence considered the combined PSA and DRE examinations as screening evidence. An experienced practitioner who has vast experience in DRE examinations interpreting feel of the Prostate, aligned with the PSA result, provides a better screening result than just the PSA. The evidence seen refers to DRE in relation to active surveillance: to quote from the Prostate Cancer Screening Economic Model: Accompanying Narrative 2025 at page 12 ;.....not receive immediate treatment but instead fall under 'active surveillance,' (or watchful waiting) where they would receive - o In the first 12-18 months: a PSA test every 3-4 months in the first-year post-diagnosis, a digital rectal examination (DRE) at 12 months, and an mp-MRI at 12-18 months; then - o From 2 years' on: a PSA every 6 months and DRE every 12 months. Why is DRE alone considered appropriate as part of active surveillance and not as a combined examination in the first place? ie PSA plus DRE.

The evidence outdated being still focused on 2020 evidence with no mention of advances in post PSA screening by MRI.

Transition trial will take at least four years, whilst no progress is made in screening decisions, and advances are taking place.

Discussion comment:

To quote from the Minutes of the 27th November ; This was to ensure that members of the committee and reference group were able to raise and examine queries about the model's predictions and have constructive discussions in order to be able to provide impartial, evidence-based draft recommendations that may then go onto become government policy.

It appears from an email received from my MP for ***** on the ***** which predates the NSC Meeting on 27th November that the conclusion and recommendation of the NSC was biased towards government policy; to quote from the letter:

This Government's 10-year Health Plan makes puts prevention at the heart of healthcare. For prostate cancer, we plan to use genomic insights (including identifying BRCA1/2 genes), combined with non-biological risk factors, to provide a risk score for prostate cancer, which will allow for earlier intervention.

Perhaps the feedback from the consultation will result in a change of policy from the NSC

Recommendation comment:

Every male over 50 is entitled to a PSA test. Others at risk over 45 are. Black men more at risk are entitled and more at risk. Men presenting at GP's are turned away if they have no symptoms (hear with my own ears). GP's are not confident to deliver DRE's. All best described as adhoc screening. Is there data of number GP PSA Tests and how many Prostate Cancers are revealed.

Other groups, e.g Fighting Prostate Cancer, CHAPS and Graham Fulford are subsidising the nation by offering screening, at costs from minimal to £35 a test. National Screening should be offered, not just to BRCA1/2, but to the high risk 45 plus group.

A base line PSA and DRE record at 50 should be established, for all men, like they are offered Abdominal Aortic Aneurysm (AAA): at 50. using specialist practitioners trained in DRE examination. Combine AAA screening with PaCa PSA and DRE. Expert DRE examiners would recognise early issues e.g enlarged prostates etc.

Alternatives comment:

Offer government grants or incentives to charitable organisations providing Prostate Screening Services and facilitate links direct to more specialist Prostate Cancer NHS Urology Services

Other comments:

If no or limited screening is introduced engage with the Hospital Charities to encourage them and their Urologists and Nurses to offer Prostate Screening sessions, as a charitable service.

Incentivise NHS Trusts and GP Practice Groups to hold Awareness Events for Patients, which would encourage take up with GP's especially if there were trained nurse practitioners specialising in PSA testing and DRE's

P887	Affected Comment: Yes. I was diagnosed with prostate cancer in *****, following results from a PSA test that I had requested at my GP surgery. I did not have any symptoms and wanted to get tested because a close friend was diagnosed and has had to undergo surgery, radiotherapy and chemotherapy Evidence Comment: Yes, I believe important evidence has been overlooked. I am not in one of the higher risk groups identified by the committee. I am a white male, no symptoms and no family history. I believe the conclusions about over-treatment are exaggerated and do not reflect current practice Discussion comment: The conclusion overlooks many men who would be in my position and appears to completely overlook the serious consequences of diagnosing men with advanced, metastatic prostate cancer. Recommendation comment: I think it should be recommended for males over 60, with no symptoms, no family history, in addition to the higher risk groups already identified Alternatives comment: By advising GP surgeries to promote PSA testing for men over 60. The senior nurse in my GP surgery tried to dissuade me from having a PSA test because I didn't have symptoms and don't have a family history of disease Other comments: The committee should look at the data from trusts that have higher rates of diagnosis and treatment. These trusts will have more reliable data than other trusts that are not looking to find prostate cancer patients so diligently.
P888	Affected Comment: I was diagnosed with locally advanced prostate cancer after a chance PSA test at the age of *****. I had no symptoms. I had what proved to be a difficult prostatectomy which took 5+ hours and which has left me incontinent and with erectile dysfunction. I believe treatment would have been less traumatic had my diagnosis been earlier, which a screening service would provide. Evidence Comment: I understand the decision was based on outdated and erroneous information. Recommendation comment: Should, see above

P889

Affected Comment:

I had a prostatectomy in ***** age *****. My elder brother died from it in ***** , aged ***** and my younger brother, aged ***** is undergoing treatment for it now. My nephew, aged ***** has just had the operation.

I worked for ***** and when I reached age ***** , I was entitled to an annual PSA test, which I continued to have even after I left that company. My PSA count was always relatively low but the test that I had in ***** showed the level of PSA had doubled. Further tests showed the level was rising and because my brother had recently died from it I decided to have the operation, "sooner rather than later". I have often wondered since, whether I needed the operation. After the operation, and for many years, I did occasionally suffer from quite severe incontinence, but I have recently started taking medication and it seems to be less severe now. My erectile function has been zero ever since.

Recommendation comment:

I don't think that screening by PSA testing for the general public will achieve accurate results. But, because of my family history, I would definitely recommend the screening of close relatives of prostate cancer sufferers. My ***** and several other nephews have been having regular PSA tests since they reached the age of ***** . And as mentioned above, my nephew was diagnosed in good time because of regular testing.

Alternatives comment:

It would appear that PSA testing, whether accurate or not, is the only way of screening for it at the present time. I think it is up to individuals to take the responsibility of being checked by their GP and take the advice offered.

Affected Comment:

I was diagnosed with Prostate Cancer at *****. ***** years earlier my GP had done a PSA test, and the result was at the upper end of normal range. I had no follow-up and after around ***** years I decided to request another test. The GP I visited was a locum and having no symptoms she advised that given my last test was normal that I probably didn't need one and that if I did, I would face many more tests including a painful Biopsy. At this point I had no idea that my father being diagnosed with prostate cancer put me at a much higher risk. The GP never asked the question.

Around ***** years after this I again requested a PSA (with my original GP), this time the result was a PSA of *****. I then underwent the usual MRI and Biopsy to confirm that I had Prostate Cancer that it was advanced and aggressive (*****).

I was treated by Prostatectomy which confirmed that the cancer had progressed to nearby Lymph nodes. In the following years I had SABR treatment until in ***** it had spread further ***** needing Chemotherapy and primary and secondary Hormone Treatment. I was now Stage 4!

In ***** at the age of ***** I decided to lose weight, improve my diet and get fit to ensure good health into old age. By ***** I was diagnosed with advanced and aggressive Prostate Cancer. I feel that I have been extremely let down by primary care, failing to diagnose Prostate Cancer at an early stage, because of outdated and misguided practices.

My quality of life has been massively impacted by the effects of the prostatectomy and hormone treatment and under a ticking timebomb, this has also affected my family of course. And now I won't now get an Old Age!!

Evidence Comment:

From my own experience and that of many others that I have met, the decision of the NSC not to recommended national screening of high-risk men (Family History / Black men) but only a very limited cohort of men with the BRCA Gene to be frankly baffling. It feels like the decision was based on outdated views on the harm that diagnosis of low-level PC would bring. I feel that the decision has too much bias on the harms of the diagnosis process versus the benefit of diagnosing at an early stage and preventing many of the 12000 a year dying, having developed stage 4 cancer like me. I have spoken to men that were found not to have PC but do not regret going through the diagnosis process.

The risks during Biopsy are much reduced in recent years with the use of MRI to identify and guide areas of concern and using transperineal biopsy.

There should also be much greater attention given to guidance and support of men with low-level PC when looking at treatment options, including active surveillance, this is just not there in adequate levels (based on my fellow suffers experience). The NHS must be responsible for preventing any overtreatment, diagnosis is not the cause, men have a human right to know.

Discussion comment:

Based on the now reduced risk of harm during the diagnosis process, the need to save 12000 men a year from dying and the cost of treating a stage 4 patient (around 2-3 hundred Thousand Pounds) I strongly feel the recommendation should have been to screen all high risk men (family

	history / black men from the age of 45) as a starting point, moving to include the remainder of all men over 50 in the future. Recommendation comment: PSA testing is not perfect but is not the reason for overtreatment and it's all we have. Please consider the thousands of men like me with stage 4 cancer because I was diagnosed too late, introduce a screening program ASAP. If the Government's final decision does align with the NSC's recommendation, I urge to keep this under close review (2-year cycle). Further improvements in testing and diagnosis could be a game changer. Alternatives comment: I would urge that in parallel GP's guidelines are updated, my fellow PC sufferers and I hear so many recent stories like mine from 2018 where GP's are discouraging and even refusing to provide a PSA test to men who qualify on age, ethnicity and family history. Other comments: Base your decision on up to date research. Balance the low cost of PSA testing against the huge cost of treating stage 4. Treat the yearly impact to 12000 men and their families seriously whilst taking responsibility for mitigating harms of treatment rather than limiting diagnosis. I don't want to see thousands of men continue to develop Stage 4 Prostate Cancer like I have due to late diagnosis like I have.
P891	Affected Comment: Affected my friend. Evidence Comment: Did a PSA test on a whim and found cancer. Recommendation comment: should be recommended.

Affected Comment:

I am a prostate cancer survivor. In ***** I had a PSA test at ***** carried out by a charity. The result was a 'Red' high alert which my GP chose to ignore. I had to insist that I be referred to a consultant using my employers health insurance. Followup PSA, MRI and biopsy test confirmed Stage 3b prostate cancer. The risks of chemotherapy surgery were explained to me and I chose to undergo prostatectomy surgery. This was completed *****. ***** I would not have been treated and in all probability the cancer would have spread (GGG progression in the report) and I would be dead by now. I am living proof that early detection saves lives. Yes I do have the predicted side effects but I had the choice to continue family life and avoid a lingering death.

My father died from prostate cancer and my mother and aunts had breast cancer.

I supported a local charity providing easy access to PSA testing. I witnessed the prevalence of RED results and saw the people who were quite clearly arriving too late to be able to benefit from any treatments.

Evidence Comment:

The report 'blames' PSA tests for the risks of over-diagnosis. It does not appear to reference the improved treatment pathways (multi-parametric MRI scans) which are intrinsically less invasive with reduced side effects.

The cost (both financial and social) of caring for people with terminal cancer do not appear to have been taken into account.

Discussion comment:

The evidence considered appears aimed at what is the perfect screening programme, not 'can we build on what is available now?'. It meets the needs of clinicians' research for the perfect treatment, not what does the population need to detect prostate cancer.

The report focuses on the harm of over-diagnosis and over-treatment. Common sense would presume that old fashioned historical trans-rectal biopsy had a high risk of sepsis and other side effects. The report 'blames' PSA tests for the risks of over-diagnosis. It also presumes that patients will not have the side effects explained to them before consenting to treatment.

The report appears to expect people to be treated without side-effects. Currently those side effects may be unavoidable collateral damage if you want your cancer treated.

Recommendation comment:

Screening should be recommended.

Early detection saves lives. If you wait for symptoms to present it is too late. Screening should be recommended for males over 40 every 4 years.

Over-diagnosis should be minimised by multi-parametric MRI scans to determine treatment paths which could include active surveillance (addressing the False Positive)

False negatives would be caught by the following 4 year test (not perfect but better than now).

Alternatives comment:

	If the definition of a screening programme is everybody is sent invitations to go to the GP to have the test done the alternative is to just allow people to ask for a PSA test on the NHS without the hassle and refusal from GPs. Other comments: See my recommendation for 4 yearly tests for the over 40s, either by screening or on request at GPs. TRANSFORM currently is researching for the perfect solution. If it is to report on 15 year outcomes then we will have to wait 20 years for a conclusion. How many people will be denied a PSA test, detection and resulting early death whilst we wait? TRANSFORM project's objective should be modified to presume that cheap PSA tests should be the first step and TRANSFORM compares alternative pathways after that.
P893	Affected Comment: Yes. I had to 'persuade' my GP (at age *****) to let me have a PSA test. No symptoms but MRI and bios confirmed cancer. RT and hormones.

P894	Affected Comment: I am writing as an individual and concerned member of the public whose family has been affected by prostate cancer (and breast cancer), and with one close relative currently undergoing treatment for prostate cancer. I also previously had many years of having worked with men with prostate cancer and their families and developing support services for them across Scotland. Evidence Comment: I welcome very much the conclusion of the review in regard to the proposed introduction of prostate cancer screening for men with the BRCA1 and 2 gene alteration. As these men are likely to be considerably more at risk of prostate cancer than other men and also at greater risk of having higher grade prostate cancer the proposal to introduce screening for this group is very positive and should help improve outcomes through earlier diagnosis. I note that the Institute of Cancer Research has however recommended ending screening for BRCA1 and BRCA2 carriers up to age 69 rather than the Committee's proposed 61 as the IMPACT trial found significant number of cancers were detected between the ages of 61-69. (I note that the Report suggests Net Monetary Benefit was positive for single screening before age 68). Discussion comment: Whilst welcoming the recommendation regarding screening for men with the BRCA 1 and 2 gene I am surprised and disappointed, however, by the conclusion not to recommend the introduction of screening for Black men and for men where there is a family history of prostate cancer. Whilst it is encouraging that the Committee will be working closely with TRANSFORM trial in regard to ethnicities and prostate cancer and further information, the Committee's recommendation not to screen Black men for prostate cancer appears surprising given the conclusion of the SCHARR report that one of the strategies that had the lowest uncertainty of the benefit to harm balance was screening Black men every 4 years from the age of 50 to 62. In addition, given that Black men in the UK are two to three times at greater risk of prostate cancer than men of other ethnicities and according to the National Prostate Cancer Audit are more likely to have higher diagnoses of prostate cancer as well as a higher rates of Stage III and IV prostate cancer than other ethnic groups and the SCHARR report's conclusion that screening Black men for prostate cancer is likely to detect more cancers amongst those screened compared to screening the general population it would appear that there is a good case for introducing screening for Black men for prostate cancer. In regard to the issue of relevant family history of prostate, breast or ovarian cancer I recognise the considerations and concerns regarding benefits and harms of screening and concerns of overdiagnosis. However despite the really interesting work in the report on calculating familial risk overall the report overall appears to too closely treat the group of men with a family history as subset of the general population, rather than particularly considering them as a distinct group of people more at risk of prostate cancer, despite the report showing that the screening of the familial group led to gains in Life Years and increases in QALYs (for those screened before 72) and cost effectiveness in several scenarios as well as lower ICERS than for the general public. Given that in the case of biologically born males who have close relatives (father, brother, grandfather, uncle) who have or had prostate cancer are more at risk of getting it themselves (with men whose father has/had prostate cancer being about two times more at risk of getting prostate cancer and a brother has/had prostate cancer about 2-3 times more at risk of getting

prostate cancer) there remains a need to look urgently at ways of targeted earlier detection/screening for this group, especially for those where there is a close familial history of prostate cancer or aggressive disease. This is particularly the case in Scotland, where I live, as levels of later stage diagnosis appear to be higher than many parts of England.

Recommendation comment:

See above

Alternatives comment:

In addition to targeted screening there is a need for greater awareness of prostate cancer amongst the population, and also about groups most at risk of it. More needs to be done to raise awareness and encourage early/earlier diagnosis.

Affected Comment:

I was diagnosed with Prostate Cancer and treated in the SBRT arm of the PACE B trial in ****.

In **** and a bit run down after being ****,

My GP requested some blood tests which included a PSA test – although I had not expressed any symptoms. The result was **** and I was referred to the local hospital. After both a TRUS guided and Template Biopsy I was informed that “***** of the cancerous ‘cores’ were of a more aggressive nature and delay does add risk” and my Gleason score was ****.

The story of my treatment was reported here ****

This also refers to this paper in the **** published in ****

I know several men who have also been treated for the disease. Most of them opted for surgery because they “wanted it out”

Evidence Comment:

The NSC does not appear to differentiate between the level of potential erectile dysfunction between surgery and radiotherapy.

During the consultations that I had prior to treatment the surgeon I met to inform me that I had cancer was clear that there was a high risk of nerve damage leading to losing the ability to have an erection after surgery.

Whereas during the consultation with an oncology registrar the risk of erectile dysfunction was described as a potential for “dry orgasms” which I have not experienced!

The lesser understood risk and the distinction between invasive or non-invasive treatment is what swayed me to opt for radiotherapy! To then be randomly admitted to the 5 course treatment arm of the trial was a most welcome bonus. I have to say that the other side effects of the actual treatment were less than forecast and absolutely tolerable – they had a minimal effect on my day to day life and only for a short period of time!

Radiotherapy treatment has progressed significantly since the early days when broad spectrum radiotherapy could more seriously affect other organs and cause some of the harms mentioned in the papers. I believe that these potential harms are reduced by the more focussed treatment.

Discussion comment:

It is not clear in the Prostate cancer screening evidence review 2025 coversheet_Final or the SCHARR Report Phase 3 Prostate Cancer Modelling_FINAL what influence the patient and public voice (PPV) had on the the discussion, conclusion or recommendation.

Section 4.9 of Prostate Cancer Screening Evidence Review 2025 Narrative_Final states “There are significant uncertainties in the data used to estimate the costs, harms and benefits (measured using EQ-5D and QALYs), and the incremental NMB for each screening strategy.”

The conclusions are based on academic analysis and do not appear to include clear patient input.

	The recommendation makes no reference to the fact that men over 50 can request PSA test through their GP who should (but cannot be relied upon) to give advice under the NHS Prostate Cancer Risk Management Programme. The decision as to whether or not to proceed is a matter of patient choice! My personal view is that Active Surveillance is most likely to exacerbate the anxiety harm referenced in the document. Recommendation comment: Screening should be recommendend at this time for all high risks groups as it is well known that men do not present themselves until it is too late! The recommendation should make reference to the fact that men over 50 can request a PSA test through their GP who should (but cannot be relied upon) to give advice under the NHS Prostate Cancer Risk Management Programme. The decision as to whether or not to proceed is a matter of patient choice! Alternatives comment: Adopt the SBRT course of treatment as a standard as a more cost effective method of treatment which is at least as curative and (based on my personal experience) has less side effects than surgery or longer courses of treatment. Update the information in the NHS Prostate Cancer Risk Management Programme to reflect the latest treatment options Put more effort into research to identify which prostate cancers are aggressive. Other comments: Wider engagement through Healthwatch and other patient groups – see this example https://www.healthwatchwarwickshire.co.uk/report/2025-12-15/mens-health-psa-prostate-specific-antigen-testing

Affected Comment:

Prostate cancer has had a significant impact on me, my family, and friends. I was diagnosed in ***** following a routine work medical that included a PSA test. I was *****, fit, white, no family history, no BRCA mutations and no symptoms. My PSA was *****, and the biopsy showed a Gleason score of *****. *****.

I had a prostatectomy, but afterwards the PSA was persistent so salvage radiotherapy with 2 years of hormone treatment followed but the PSA rose again. Scans showed metastases on a lymph node so stereotactic ablative radiotherapy (SABR) followed but after treatment new tumours were visible so on to systemic treatment with lifetime hormone treatment (ADT), ***** sessions of chemotherapy (Docetaxel) and then Enzalutamide (ARPI) until the PSA started increasing again – the cancer was now castrate resistant. ***** cycles of chemotherapy (Docetaxel) followed.

Until this point I had never had symptoms from Prostate Cancer itself but in ***** I developed pains that were diagnosed as Metastatic Spinal Cord Compression which required emergency admission to A&E, ***** in hospital and palliative radiotherapy to my spine. A course of ***** cycles of Chemotherapy (Cabazitaxel) had since started and I am on cycle *****. This is the last line of treatment available. The cost, so far, to the NHS has been hundreds of thousands of pounds.

I retired early after being made redundant from my ***** and recognising that trying to find a new job in your late 50s with a non-curative cancer diagnosis hanging over you, despite all the apparent legal protections, was futile.

At the point of my diagnosis ***** started visiting his GP for an annual PSA test which gives him the satisfaction of knowing every year so far that his PSA level is well within the normal range for his age. He now knows that as he has ***** with prostate cancer his risk is increased, and he takes steps to do what he can to mitigate that risk. This provides great relief to his wife and children and to our mother (*****).

Friends and colleagues who are aware of my diagnosis have also taken into their own hands the pro-active step of getting regular PSA tests in the knowledge that whilst imperfect it is the best test available now.

My cancer is not curable and became Castrate Resistant ***** months ago and my prognosis is terrible (mean survival for Castrate Resistant Metastatic Prostate Cancer is approx. 24 months). Dealing with the side effects of treatment is nothing when compared to living with the sword of Damocles hanging over you.

My experience is that the emotional, physical, and social impacts of this disease are profound, and earlier detection could make a real difference to many families like mine.

Evidence Comment:

Commenting from a non-clinical but informed patient perspective, the Stakeholder group of “customers” identified in Table 1 of the CSHARR report surprisingly did not include any individuals with any of the individual risk characteristics of gender, ethnicity, or family history (incl. BRCA).

The levels of “overdiagnosis” shown by the model are high. Work needs to be done to break the link between overdiagnosis and overtreatment. Irrespective of whether there is a screening programme or not there needs to be improvements in the patient information provided and the shared decision-making process. Tools like Predict Prostate and the “Tackle Making Sense of It” programme need to have wider use.

The 2025 National Prostate Cancer Audit measures overtreatment and shows England as running at 7% of men with low-risk disease having radical treatments but in a wide range from 2% to 40%. This is 382 men in absolute terms.

Table 20 and 21 shows DRE costs. The GIRFT guidance which aims to improve diagnosis and treatment times for men with suspected prostate cancer does not appear to be the model used.

Table 27 and Figure 10 show the annual costs from time of diagnosis for a stage 4 diagnosis drop considerably in the third year. This is not my personal experience and the experience of others. I know men who have been on ARPI treatment for 9+ years.

Is there any accounting for the costs incurred by the proportion of men who require a surgical intervention within 2 years of a radical prostatectomy (England average 6% range 0-20%) and the proportion of men receiving a procedure of the large bowel and a diagnosis indicating radiation toxicity (England average 8% range 1 to 16%) as identified by the National Prostate Cancer Audit 2025. If these are included what would the impact be of reducing these costs through the adoption of best practice?

The R programming language used was version 4.3.2 (31/10/23). There have now been 8 updates since with the current version is 4.5.2 (31/10/25) there is no comment on the relevance of the version used.

PSA and Biopsy uptake rates as per the CAP trial of 36% and 85% do not seem to be “realistic uptake rates”. Compare with Bowel Cancer Screening: Approximately 67.6%–71.8% (2023/24 – 2024/25). Breast Screening: 64.6%–69.9% (2022/23–2023/24). Cervical Screening: 68.8% (2023–24)

PSA baselines, PSA density and PSA Kinetics were all mentioned but their role in the diagnostic pathway was not expanded upon nor how the model could be adapted to include these as predictors.

Discussion comment:

I strongly agree with the SCHARR conclusion page 173 that “Future research should explore men with a family history of aggressive disease (e.g. early onset cancers) would be cost effective;”

My experience is that many of these men are already getting regular PSA testing, but that data is not being centrally captured or used.

Much is made of the harms of overdiagnosis and less seems to be made of the harms of years with a Stage 4 diagnosis with the end point of death from Prostate Cancer.

In my experience of running prostate cancer support groups over 8 years no men have regretted having radical treatment. They might regret the outcomes but not the decision to have treatment. They had agency and made a treatment decision in full sight of the known information about their cancer in collaboration with trusted medical professionals. It is not clear how patient agency gets factored into screening assessments.

Recommendation comment:

Screening for high-risk groups is a starting point. Men with BRCA mutations is a starting point but what is the next subgroup that should be targeted? Is it Black men with a family history of aggressive prostate cancer? What data needs to be gathered to evidence this one way or another?

Saving lives should be a priority. After a ***** career that held employee health and safety as paramount importance – I know that many employee safety mitigation measures are put in place to ensure no employee lives are lost. Unfortunately, the HSE report 124 employee lives lost at work in the UK in 2024/5. Legislation and a huge effort go into trying to minimise this at a cost to the business and also to the inconvenience of employees.

If a case was presented that health surveillance to a workforce population of 1000 male workers aged between 50 and 60 would save 2 lives but 12 may be overtreated (as per the CRUK infographic). Then we would work hard to minimise the 12 overtreatments but also work with our workforce and their representatives to save the lives of 2 colleagues and not idly stand by. Why do we have a different philosophy between employee safety and employee health?

Alternatives comment:

In the absence of any screening programme all men need to know what their personal risk is and what the best thing is that they can do to protect their health and catch a cancer that can and needs to be caught early and not catch a cancer that doesn't need a treatment that may give them life changing side effects. To do this there needs to be better education on risk. Improvements in shared decision-making process, including the decision whether to have any testing, support to reduce regret. Improvements to diagnostic pathway to reduce harms in the pathway. Improvements to treatments to reduce harms in treatments.

There needs to be a better understanding of the Natural History of the Disease through better and complete data collection up to and including better use and understanding and public communication of all PC mortality data.

PSA blood testing needs to be better organised, controlled and consistent – taken away from GPs. In the absence of this there will be an increase in community and workplace testing, home test kits on Amazon etc.

As an individual I understand there is a big difference between managing the health of a population and me managing my own health and life. The individual personal concern will be missing a cancer that could be cured. A better middle ground needs to be found especially now that the recommendation is for targeted screening for those with BRCA mutation.

Increase the capacity of MRI in the UK. The BMA already report that the UK has fewer scanners per million people than any EU country. Not only are more machines needed but also the trained staff and supporting AI.

Work closer with employers and Trade Unions on matters of employee health. The Police Federation, for example, hold regular PSA testing events for their members.

Other comments:

Review employment protection rights for those with a BRCA mutation but not diagnosed with cancer.

	Use the model to work backwards to determine the sensitivities of the model and what criteria would deliver cost-effective screening that minimises overdiagnosis. Maintain the model so that it can be used dynamically as and when new diagnostic pathways such as Stockholm-3 are better understood. Work more closely with patients and communities and male health organisations such as the Men's Health Forum who will be possibly more interested in limiting harms. I am not a statistic. I am a real person with family and friends. I am a son, husband, father, brother, uncle, and I will shortly be taken by this disease. Early diagnosis of significant cancer is an urgent and important matter that needs to be better controlled than the ad-hoc inequitable manner it is dealt with now.
P898	Affected Comment: My husband has had prostate cancer. At the age of *****, he had blood in his semen – just once. He went to the GP who did a DRE and said everything seemed fine. When my husband insisted on further investigation, she agreed to do a PSA test. This showed a higher than normal PSA level. He was then referred to a specialist who did an MRI first and, based on the results of that, a biopsy. The biopsy showed that my husband had prostate cancer but low grade (Gleason *****). Because we had private insurance at the time, he was then put on a cycle of annual MRIs. At the third of these, it showed that the cancer was growing and was starting to break out of the capsule, so he was recommended for surgery. At the point he had surgery, the cancer was regraded as *****. In those 3 years, he never experienced any more symptoms. Had he either NOT gone to the GP at the first symptom, or had accepted her initial reassurance, he would almost certainly, by now, have stage 4 cancer. As it is, at ***** months since surgery, his PSA level remains undetectable. We should not be leaving this to chance. Every man over 50 (or younger if they have increased risk due to ethnicity or family history) should be screened to ensure this is caught at a point where the disease is treatable. Evidence Comment:

	Not every prostate cancer is treated. Watchful waiting is an acceptable strategy for small cancers. This means the risk of 'over-treating' should be reduced. Recommendation comment: Screening SHOULD be recommended. It only requires a blood test initially. We spend much more on mammograms and that has demonstrated a reduction in deaths from breast cancer. Alternatives comment: You could easily set up a screening service that works like mammograms, where a small unit staffed by phlebotomists could set up in a supermarket car park and men in the local area are invited every 2-3 years. The burden does not have to be placed on GP practices.
P899	Affected Comment: Initial speculative PSA Test Spring *****, Diagnosis in ***** after 2nd biopsy, non nerve sparing RALP after 4th biopsy (template) *****, result was failure to remove it all, potentially due to procedural delays and the fact that I live on my own. PSMA Petscan ***** when PSA levels high enough. Indicated recurrence. Offered Radiotherapy/ADT per NG131. Offer turned down on Quality of Life grounds. Repeat PSMA Petscan ***** indicates spread. Restricted range of travel due to short urination intervals. On the plus side it has given me a cause to campaign on. Discussion comment: Making a direct connection between a PSA test and the diagnosis of prostate cancer is scientifically wrong. All a PSA test can indicate is that something is wrong within the prostate. The level of PSA in the blood is an indication that there are unhealthy cells within the prostate. It is a biopsy that determines whether someone is diagnosed with cancer. an MRI scan can indicate where the biopsy needs to be sited and act as a comparative for future scans to detect any potential progress of the size and location of any disease. Again it cannot be used to diagnose prostate cancer. The economic model should not be taking into account any harms arising from a test that is being made out to be harmful through a misunderstanding of how it is being used. These harms may arise at a later stage of the diagnostic process but the prostate is in a totally inaccessible location. Recommendation comment: yes. For 40 yr olds. It would serve as a benchmark and as the likelihood of cancer suggestion is small, the impact on those men would be far less as the immediacy would not be a factor. on a practical basis it could be merged in with an MOT type of blood tests thus cutting GP time. The prevalence figures for 2022 indicate that there were 234 people aged between 35 and 44 with another 1106 aged between 45 and 49 who had prostate cancer. in view of the extent of late

diagnosis cases, in *****, based on the NDRS rapid figures, and comparable to the situation in the north of England we have a potentially open cheque book scenario that the country cannot afford. I am looking into seeing if there is a financial case to be made that late stage detection is significantly more expensive than early detection.

Alternatives comment:

The provision of a 3D visual representation of the prostate scans would aid understanding of the extent of any abnormality greatly. Consultants do not have time and potentially the equipment to do this. In ***** i asked if this was available and was told not on the NHS. How can a man make decisions on partial information. It was available to Kate Garraway in her TV series some years ago!

Make the guidance of NG131 more mandatory. I have the impression there is not enough compulsion in the guidelines. There is a great incidence of people not being able to get a PSA test through there GP. A short duration helpline could establish the extent of this practice. I had to cancel a template biopsy under general anaesthetic as I live on my own. i had the procedure 2 months later. All because it was not flagged up on the system when the consultant made the booking. That may be why the RALP failed.

There is no capability to be proactive as the funding model prevents GP's from dealing with situations that the patient envisages ahead of time. I have a personal experience of this resulting in a £600 taxi fare from *****!

Other comments:

yes to follow up on the APPG for Prostate Cancer recommendation that the topic should be covered in schools. school students are affected by Prostate cancer in their families and such awareness may open up more men to being able to discuss this disease with their families.

Affected Comment:

yes. This is an additional submission to my submission of 20th Feb 2026

Alternatives comment:

Further to my comments on the nature of a PSA Test, I now note that the introduction of mpMRI scans prior to a biopsy was adopted 2019 to 2020 but in fact my first Biopsy in ***** was after an MRI scan. The latest PCRMP document was last updated 29 March 2016.

It refers to Guidance for GP's and also for men seeking a PSA Test.

I consider it to be a high priority that the guidance be updated as the language and terminology referring to false positives and negatives related to a time when a blind biopsy followed a PSA test or DRE. The content of the discussion that a GP needs to have with a man over 50 is therefore significantly behind the times. The PSA test has become the test for the healthy functioning of the prostate in the same way tests can determine the health of the kidneys. The PSA test seems to have taken the blame for the resulting discoveries arising from a biopsy. MRI scanning has therefore rendered the charges of over diagnosis and over treatment to be greatly reduced in significance and has changed the nature of the harms that might be encountered going forward. I have noted from Facebook groups that on the recognition of their cancer diagnosis there is a desire amongst men to get rid of the cancer instead of active surveillance which might then be classed as overtreatment, This desire may well stem from a lack of

information and tests to indicate that the cancer is and will remain indolent have yet to be created. One can only know in retrospect. I was diagnosed in ***** with ***** considered to be indolent but in ***** a 4th biopsy showed it to have progressed to *****. I ended up with a RALP that failed to remove all the cancer and thus the whole diagnosis process of 4 years was 'legitimised' and no longer considered unnecessary.

Other comments:

I think that with the number of occasions that men have been refused a psa test by doctors and the time allowed to deal with the discussion of the pro's and cons (10 minutes for consideration of the implications of the pro's and con's of mri scans and biopsies is not enough time to enable a satisfactory consideration to take place – but that is all they are being given), an online educational module could be developed whereby patients could be educated on the processes involved. It could contain a standardised list of the ramifications of a PSA Test – up to and beyond a biopsy – and allow for time to reflect on what they decide as a result. At the end of this module a certificate of completion could be produced to be taken to a GP, whereby the GP would then only have to consider to agree or otherwise to a psa test as they do now. They should be compelled to explain why they are refusing (in general terms) as this causes great frustration/anger. The patients could always revert to charities that can provide the test for a moderate sum and thus circumvent the gp approval process. (I can understand that doctors may be reluctant to turn someone down on the basis that their considered life expectancy is no longer than 10 years!) This would speed up the process and establish continuity throughout England.

Affected Comment:

8 years ago, aged ***** that I started getting regular annual PSA tests even though I still had no symptoms.

The results started around ***** and slowly crept up to ***** and each time I was told that as long as it remained below 5, all was fine.

In ***** it had crept up to *****.

Armed with the WRONG guidance that anything below 5 was OK I did nothing. What I now know is that ANY SMALL RISE IN PSA LEVELS is a perfect indicator of problems ahead. No-one ever told me this and my GP Surgery certainly never picked up on it.

In ***** , a locum nurse, refused another PSA Test on the basis that all tests were unreliable and I still had no serious symptoms and Covid was just starting.

In ***** , my next PSA Test was ***** and a biopsy swiftly followed, giving a Gleason score of 7 (4+3), then a bone scan which was clear initially was a huge relief.

Then a whole body scan, which was clear and a Dexa scan, also clear.

I was told that the cancer had spread through to 3 Lymph node stations, which was a worry, but no more as it was controllable.

Later a PET scan gave me the nasty truth that in fact I had bone mets in my pelvic bone, my back and ribs.

Evidence Comment:

I feel that the decision has too much bias on the harms of the diagnosis process versus the benefit of diagnosing at an early stage and preventing many of the 12000 a year dying, having developed stage 4 cancer like me. I have spoken to men that were found not to have PC but do not regret going through the diagnosis process.

The risks during Biopsy are much reduced in recent years with the use of MRI to identify and guide areas of concern and using transperineal biopsy.

There should also be much greater attention given to guidance and support of men with low-level PC when looking at treatment options, including active surveillance, this is just not there in adequate levels (based on my fellow suffers experience). The NHS must be responsible for preventing any overtreatment, diagnosis is not the cause, men have a human right to know.

Discussion comment:

Based on the now reduced risk of harm during the diagnosis process, the need to save 12000 men a year from dying and the cost of treating a stage 4 patient (around 2-3 hundred Thousand Pounds) I strongly feel the recommendation should have been to screen all high risk men (family history / black men from the age of 45) as a starting point, moving to include the remainder of all men over 50 in the future.

Recommendation comment:

PSA testing is not perfect but is not the reason for overtreatment and it's all we have. Please consider the thousands of men like me with stage 4 cancer because I was diagnosed too late, introduce a screening program ASAP.

If the Government's final decision does align with the NSC's recommendation, I urge to keep this under close review (2-year cycle). Further improvements in testing and diagnosis could be a game changer.

Alternatives comment:

I believe that far too many GPs and Nurses are totally wrong to refuse or discourage patients to have a PSA test.

It is an out of date stock answer and being in the position I am in now, with Terminal cancer, I have met at least another 20 or so Stage 4 Prostate Cancer sufferers with the same story as myself of being turned away by their local GP Surgery.

This must equate Nationally to something in the region of 20,000 deaths in the next 5 years.

Other comments:

I believe that in recent years over treatment is less of a problem and that the National Guidance for all GPs should be to NEVER refuse a PSA test.