

Targeted Lung Cancer Screening – Public Consultation Responses

1. [REDACTED] Member of the Public

Affected Comment:

I was diagnosed with stage four lung cancer at 28. This was not investigated properly at first due to my age and covid. Early diagnosis is vital, and non smokers should not be excluded.

Recommendation comment:

Always, as above.

I was diagnosed with stage four lung cancer at 28. This was not investigated properly at first due to my age and covid. Early diagnosis is vital, and non smokers should not be excluded.

Alternatives comment:

Recommending anyone with symptoms such as a cough that doesn't go away comes forward for investigations. Yes it could be a chest infection, but as I learned the hard way, it can also be stage four lung cancer

2. [REDACTED] Member of the Public

Affected Comment:

Yes me but bc I have cushings syndrome it cwas misdiagnosed

3. [REDACTED] Member of the Public

Affected Comment:

I'm behind this screening 100%. Both my maternal grandparents died in their 50's from lung cancer. My grandad died before I was born and my Nan died when I was 6 years old, mu Mum was 28 years old. She died 4 years ago to this disease, although they caught hers early, it was really aggressive and she died within 6 months of initial diagnosis, she had just turned 71. Now her sister, aged 77 has been diagnosed with stage 4, she's receiving palliative care. I strongly believe ours is genetic and as there are no genetic testing for lung cancer, screening for me and my family is the next best thing. I know people do survive it, but not in my family's case.

Recommendation comment:

See my original comment.

4. [REDACTED] Member of the Public

Affected Comment:

Yes, my Mum was diagnosed with Lung Cancer at age 59. She had never smoked. The cancer was discovered at a late stage, and she passed away within 6 months of diagnosis with a massive impact on her quality of life between diagnosis and death due to secondary bone cancer, rendering her pretty much immobile.

Recommendation comment:

Should be recommended. Too many people are diagnosed at a late stage meaning that their prognosis is poor. By catching cancers early it gives people a better chance of survival.

Screening should be offered to all, not just those considered high risk, as it's often in those who we deem to be low risk, where the cancer isn't detected until it's too late.

Alternatives comment:

Awareness via media campaigns, wellness checks by GPs.

However, often it's too late for people by the time they are diagnosed, so early diagnosis via screening or enhanced GP knowledge is the most important element.

Once diagnosed, successful treatments are needed, as well as support for those with a poor prognosis.

Other comments:

Education that lung cancer does NOT only affect smokers. There is a general assumption that only smokers are at risk, and that anyone with lung cancer has it as a result of their own behaviour, therefore less sympathy.

5. xxxx xxxx Member of the Public

Affected Comment:

My father had lung cancer an early diagnosis of stage 1a which he had surgery for but it came back 2 years later. It is a devastating disease on the patient and whole family. Improvements need to be made asap to help others get an early diagnosis.

Recommendation comment:

Screening should be recommended as so much development in early stage diagnosis of other cancers lung should have the same regime.

Alternatives comment:

X-ray should be done by GP at an early stage not months down the line after antibiotics.

6. xxxx xxxx Member of the Public

Affected Comment:

I have lost 3 members of my family to this dreadful disease.

Two of them were smokers but one, my mother, never smoked in her life but was exposed to a large amount of passive smoking due to her occupation.

I too have never smoked but was exposed as a child to passive smoking. I'm highly concerned about this condition affecting me but I'm currently not eligible for any lung health checks taking place in my area.

I am desperate for there to be a national screening programme for this dreadful cancer

Recommendation comment:

Yes i definitely think there should be a national screening programme as it is the second biggest cancer killer in the UK

Alternatives comment:

Education of GPs.

My mum was stage 4 before her GP took her seriously and sent her for an x-ray but by then it was too late

Other comments:

I think the local lung health checks that are taking place should not be focused on smokers as people who don't smoke also suffer from lung cancer and seem to be neglected in all of this

7. xxxx xxxx Member of the Public

Affected Comment:

Almost 11 years ago in May 2011 my 41 year old husband got the horrendous news that he had stage 4 non small cell lung cancer, he was fit and a non smoker. He fought as hard as he could but lost his fight on 30/07/11 after only 10 weeks.

He left behind a widow and 2 daughters.

He had symptoms and went back and forwards to drs surgery, being fobbed off with antibiotics for a chest infection. By the time he had a chest X-ray and was called to the hospital to see the respiratory consultant it was too late – we were told that they were sorry but John had stage 4lung cancer and it was too advanced they could not cure him but offered chemotherapy and radiotherapy as palliative care.

Imagine as a fit 40 year old man with a wife and 2 daughters how John must have felt – devastated doesn't come close.

So you see this is why we desperately need screening for lung cancer, to keep loved ones with their families.

To stop wives becoming widows, and children without a dad, mothers without sons, friends without friends, and the list goes on.

This is 1 I'd the biggest killers – screening does save lives, look at breast, cervical and bowel screening.

It is important – please please introduce a screening programme for people at risk 🙏

Recommendation comment:

Screening should definitely be recommended.

Alternatives comment:

We know that early detection with any cancer saves lives – more money and health messages should be portrayed to the public.

8. xxxx xxxx Member of the Public

Affected Comment:

I have not been directly affected but I would be very keen to see Northern Ireland included in any future consultation, we always seem to be the last to be included.

Recommendation comment:

Screening should definitely be recommended, please include Northern Ireland.

9. xxxx xxxx Member of the Public

Affected Comment:

My father died from Lung Cancer.

For some years before diagnosis he had a series of chest infections, or what seemed to be chest infections. If he had been screened a few years beforehand it might have been found that the early stages of lung cancer was causing his symptoms and treatment might have been an option.

As you will know, lung cancer can be a very slow developing cancer but by the time he was diagnosed it was too late for any treatment.

Screening might have given us a different outcome.

Recommendation comment:

Yes. Early detection always increases the likelihood of survival.

10. **xxxx xxxx Member of the Public**

Affected Comment:

We long just as ncridinke Dadbto lung cancer in 2018, he was only 67 years old, had just retired and was looking forward to finally be able to spend a happy and what we all thought would be a long life enjoying time with my mom and our family.

Sadly, by the time he showed symptoms severe enough to be looked into he already had stage 4 lung cancer which had spread. He had tests in May, was diagnosed in June and we lost him in October, October 8th 2018, my 38th birthday.

This cruel disease took a wonderful man from us in just 4 months – and we had to watch him suffer and wither before our eyes, he had to have an oxygen machine at home within a month of diagnosis and was in constant pain, he had a cocktail of drugs and an driver in his arm, he was so l'll and suffering... and we couldn't help, it was just the worst thing in the world for us and especially for him, our hero who worked hard and loved his family and friends fiercely had to go thjrough the worst end – with screening this could have been caught early and he may still be with us... and I would have to watch my mom, so lonely in the world without her soul mate – they had been together for 50 years and should have been able to enjoy retirement together. Screening could help so many families avoid the heartache we have endured – and allow so many to live the long happy life they deserve! Please please make lung cancer careening standard, the same as mammograms / smears etc... you can't put a price in a life!

Recommendation comment:

Yes screening should be recommended, for all the reasons I have given above

Alternatives comment:

Routine chest X-rays, shadows may be picked up earlier to allow early diagnosis and better prognosis

11. **xxxx xxxx Member of the Public**

Affected Comment:

Yes at 51 after being diagnosed with primary breast cancer I asked if I was going to be screened for others and told no. 6 months into my diagnosis I had a PICC line fired and saw the cancer on my chest X-ray. I then went to my GP to discuss what I had seen. During my chemotherapy I was diagnosed with Lung cancer. Covid hand caused a significant delay in my diagnosis as I had been advised I was asthmatic 8 months before.

Evidence Comment:

Early identification helps people like me with a genetic mutation for EFGR pos possibly live a full and active life following a lobectomy and targeted therapy

Discussion comment:

Please Give people like me a chance

Recommendation comment:

It should be recommended

Alternatives comment:

Support a public health programme that explains you just have to have lungs to get lung cancer and share the symptoms widely.

12. **xxxx xxxx Member of the Public**

Affected Comment:

We lost my mum at 56 due to late diagnoses and postcode lottery.

Evidence Comment:

No I think early detection is key

Recommendation comment:

Yes. even the slightest head start is absolutely vital

Alternatives comment:

Research as it's severely under researched

13. **xxxx xxxx Member of the Public**

Affected Comment:

Lost my dad to lung cancer 3 years ago and feel lung cancer screening is needed as much earlier stage

14. **xxxx xxxx Member of the Public**

Affected Comment:

I live in **xxxx** and I believe we have the highest numbers for lung cancer.

In 2016, I lost both parents before I was 40 to lung cancer.

My Dads symptoms were hidden behind COPD, when identified, he was given 4 weeks to live. Identified too late! Dad was 74 years old.

My Mum has previously had a lobe removed due to cancer and had a lump to be watched. After falling off the review list she got her doctor to re-refer her and when scanned, they said there was no change. Months later, her health deteriorated and after doctors appointments and 3 visits to A & E, she eventually underwent a full scan to find she had lung cancer, which had spread to her bones, spine and brain. Between deterioration and passing away was about 6 weeks. Missed opportunity to catch a change in the lump. Mum was 67 years old.

Both could have been identified earlier, my parents may still be here. As a family, we would welcome testing for lung cancer.

Recommendation comment:

Should be recommended as per my personal experience above. Loss of two parents too early due to missed opportunities to identify cancer.

Alternatives comment:

Prevention is better than cure.

Screening should be available for all as standard.

Options for potential reduced cost screening between standard screening could be made available for those who wish to pay. I have no idea about costs, but this could also identify cancers early and cost less overall.

Other comments:

More advice available on symptoms, when to go to the doctors and assure people this is not a waste of time. Too many people live with health issues and don't go, leading to late notification.

Do not rely on X-rays. If something is wrong and unexplainable, from X-ray, go for a more detailed scan. My mum had hip trouble which prevented her from walking in the end and the X-ray showed nothing. The full body scan showed her hip had fractured from the bone cancer.

Quality assure follow up appointments for those who have previously had cancer, ensuring they are never forgotten, preventing unnecessary deaths.

Increase testing for those with other conditions which could mask cancer I.e COPD

Circulate this as widely as you can... so many people have lost their loved ones too early. I am pleased to see this has some recognition. I hope this progresses and saves others.

15. xxxx xxxx Member of the Public

Affected Comment:

Yes I have been affected by lung cancer, at age 52 and a non smoker, I was found to have a stage 1 tumor in my lung, this was only discovered after having had a heart scan, a few weeks prior to this I had a chest xray which did not detect the tumor. If I hadnt been sent for the heart scan the tumor may not have been discovered until it was much bigger and may have been inoperable, but thankfully I was able to have curative surgery and have been cancer free for 9 years, It is vital that this terrible disease is detected at an early stage and I feel very strongly that we need a screening programme for lung cancer, there has also been an increase in many who have never smoked, and like me had been exposed to passive smoking as a child, I know the proposed screening will only be for smokers but its better than nothing at all and would save many lives. I feel very emotional writing this as I have recently lost 2 family members who were only diagnosed at stage 4 lung cancer, sadly it was discovered too late for them, this makes me so angry as screening may have saved there lives, It would be amazing if screening was approved, its been a very long time coming !

Recommendation comment:

Yes, screening should be highly recommended for early detection and would save many lives.

Alternatives comment:

I really dont think any alternative would be better than screening.

Other comments:

Stamping out the stigma of smoking and lung cancer, wether someone smokes or not, nobody deserves to get lung cancer !

16. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with stage 4 lung cancer with no obvious ir usual symptoms. With a family history of lung cancer had I had screening my cancer could have been found before it became incurable.

Lung cancer is usually diagnosed in the late stages due to lack of screening.

Recommendation comment:

Should be recommended to save lives

Alternatives comment:

Breast & cervical screening is available for all women but not lung screening when lung cancer kills more women than these cancers

17. xxxx xxxx Member of the Public

Affected Comment:

Lung cancer effected my family. My grandad was in his early 70s when diagnosed with stage 4 lung cancer and died a short 6 months later. A national screening programme could have changed this. If he was diagnosed whilst stage 1/2 then he would have had a much better chance of survival and more treatment options.

Recommendation comment:

Screening should be recommended. It is a well known fact that early diagnosis is key.

Alternatives comment:

Screening so early detection and diagnosis of disease.

18. xxxx xxxx Member of the Public

Affected Comment:

My dad was diagnosed with stage 4 lung cancer in August 2021, was told he had 4 months without chemo, 12mths with, he died on xxxx September 2021, he did smoke but devastated xx

19. xxxx xxxx Member of the Public

Affected Comment:

My mum had lung cancer.

Recommendation comment:

Yes, it should be recommended. A lot of people associate lung cancer with smoking and therefore think that if they aren't a smoker they will be ok. This is not true, anyone can get lung cancer and it definitely

should be screened for like other cancers are. My mum found out she had lung cancer after an xray for something completely unrelated shown a shadow in on of her lungs. She had no symptoms of the deadly cancer, and she was a non smoker! she was quickly operated on for a lobectomy (removal of 3/4 of one of her lungs).

It was absolutely heartbreaking to see your strong mum so vulnerable and go through years of scans and hospital appointments to get the all clear.

If she never had that xray she probably wouldn't be alive today. A simple screening can detect lung cancer early enough for it to be treatable.

My mum is one of the lucky ones, but we cannot guarantee such luck for everyone else.

Please make screening recommend

Alternatives comment:

Educate people more on the fact its not just smokers who are affected by lung cancer. There is such a stigma attached to it. Make people more aware of the symptoms as many people think its just a persistent cough that defines lung cancer.

Saying this, I do not think that this alone is enough, people need to be educated on the facts as well as being offered screening.

Other comments:

Put yourself in our shoes, the patients who have survived and have the scars to prove it. The shoes of the loved one who deal with heartbreak. The empty shoes of the lives that have been lost when they could have been saved.

20. **xxxx xxxx** Member of the Public

Affected Comment:

No

Evidence Comment:

It is of concern that the various screening program trials were too different to produce consistent and comparable results, so it is difficult to reach a fact-based conclusion. That seems to be wasteful to me.

Discussion comment:

There is way too much focus on cost rather than quality of life. This is the case with NHS in general and it is frustrating for patients when they cannot have treatments or medication or tests etc that would improve their QoL.

Recommendation comment:

I think that screening should be offered, along with the facts of its benefits and potential harms eg unnecessary procedures. The pain from, and risks of, some of these tests are always understated to patients which results in less trust in the medical profession. For example I do not participate in breast cancer screening because of the pain – not just at the time but bruised painful breasts for several weeks afterwards – it causes me, and am unable to get referred for US screening instead which is just cruel. The risk of harms should also be stated so that people know the truth rather than being gaslighted and can make informed decisions. People other than smokers should be invited (eg woodworkers, children of

smokers, etc) and I have no idea how a list of ex-smokers could be produced from medical records – I have seen mine and they are full of gaps and errors, and the most important things are not even mentioned (eg – I have a heart arrhythmia and it is not mentioned so I get prescribed drugs which are contraindicated and then dismissed when I describe serious adverse side effects; I am sure I am not alone). I think that a public campaign that reaches everyone would be preferable.

Alternatives comment:

I think that many patient issues are dismissed until it is very late in the illness. For example, I have been prescribed powerful antibiotics, which have caused me severe long-term digestive issues, for 'sinus headache' which has finally been diagnosed (by my non-medical partner! – GP laughed at the suggestion and I really had to push to get even a trial of triptans) as migraine and treated properly – at age 64. The same thing applies to coughs, diffuse chest pain, feeling under the weather / tired, etc and, especially in women, gets treated as psychosomatic with antidepressants. I think this should change, but it is difficult with the current 10-minute GP appointments with the 'one appointment, one patient, one issue' motto which means that a cough and tiredness end up not getting associated. The poor quality and specificity of GP notes, and lack of continuity in that any GP from a practice calls you so none of them get to know you and what your 'normal' is, plus results in having to repeat info on each call which uses up large chunks of that 10 minutes is also very unhelpful. I think that if there was a higher index of suspicion by GP's, rather than patient concerns being dismissed and poo-pooed or patients being laughed at (as has happened to me many times, and generally I was proved correct in the longer term but suffered emotionally as well as physically in the interim; I won't bother to tell you how often I asked 'how can these be sinus headaches when I don't have a stuffed up head or runny nose etc?') and patient concerns thought about and investigated then more serious issues would be discovered and hence treated earlier in the disease course. This would often result in savings as well as the, in my view, far more important QoL.

Other comments:

The current GP appointment process requires that you fill in a form. One of the questions is whether you have any ideas about the cause of the problem. The end result of this is that we all google the symptoms and put down what we find. The GP, because they have no idea about you at all, except some really weird and incomplete previous notes, start by asking you about that. This puts the onus on the patient and absolves the GP from using their medically-trained brain. Yes – you sometimes get the drugs for whatever you think it is based on Dr. Google, but is that correct? Why not just open prescribing to the general population? The effect would not be that different... and the NHS would save a fortune. It really is very challenging to have any sort of proper conversation with a medic and to get their advice about whether to have a test or not, whether to have a procedure or not, what any complications might mean for you, and so on. I've been told all sorts of things – including that I most definitely had stage 4 ovarian cancer and needed an urgent hysterectomy – and avoided serious operations by insisting that proper tests were carried out first and it was found I did not have any cancer etc. So just having a screening program without proper support about whether to have the next stage test, biopsy, or whatever, rather than the current conveyor belt of 'if A then B' will result in more harms than benefit. If you look at the numbers for breast screening of women without any self-identified lumps etc you will find that it causes more harm than good – 3 women are harmed for each 1 diagnosed. If there is a screening program for lung cancer it needs to be a detailed CT scan read by properly qualified specialists, perhaps with the help of good AI, not just a plain chest x-ray, to reduce harms. Good luck with making this decision, I don't think you have proper facts on which to base it.

21. xxxx xxxx Member of the Public

Affected Comment:

Lost my mother in law far too soon to lung cancer. She was a non smoker in good health and she didn't show symptoms until it was already too late. She never got to see the birth of her grandson. Nobody should have to experience that grief if it could be avoided by screening.

22. **xxxx xxxx** Member of the Public

Affected Comment:

Expand screening to non smokers. My mother passed away from lung cancer 8 years ago after a six and a half year battle. She never had any symptoms. Her cancer was found when she went to the hospital after she injured her shoulder. An xray from the chest up revealed her tumor, but by the time it was discovered, the cancer had already spread to her chest wall and was inoperable. For six and a half years we waited and hoped for new treatments, and new options. The only targeted therapy for her EGFR mutation was Tarceva, which my Mother had terrible reactions to, but she endured the extreme discomfort just to give herself a better shot at life. If we gave EVERYONE the chance to be tested regardless of a history of smoking like we do for women and mammograms, imagine the lives we could save from this terrible disease. Lung cancer doesn't discriminate. If you have lungs you can get lung cancer whether you are a smoker or not

Discussion comment:

Expand screening to non smokers!

Recommendation comment:

Because does not discriminate. Anyone can get lung cancer

Alternatives comment:

Screen for markers and genetic mutations. any targeted therapies can expand life spans and quality of life.

Other comments:

Lung cancer is the least funded cancer research because of the stigma with smoking. We need to erase this stigma and educate not discriminate. Anyone can get lung cancer!

23. **xxxx xxxx** Member of the Public

Affected Comment:

Yes my mum had a routine xray & diagnosed stage 4 & died within 6 months of diagnosis. It's shocking & scary we are not screened, needs to change. I will never get my mum back

Recommendation comment:

Yes, it could have saved my mum's life

24. **xxxx xxxx** Member of the Public

Affected Comment:

Both my nan and grandad have been gravely affected by lung cancer. My nan who's 80 was diagnosed 15 years ago. She could not have chemo etc and had to have 1 lung completely removed. From that day her life has never been the same. Unlike all the paperwork and advice we received she was unable to walk weeks later for not being able to breathe. Since that day she cannot talk well for shortness of breath. She could walk more than a couple of meters for shortness of breath. She needs oxygen daily. Had she been

screened her cancer could have been caught before the removal of one lung was needed and the last 15 years would have given her a quality of life she's been unable to enjoy. My grandad was diagnosed approx 6 years ago. He did have chemo and we did manage to have another 4 years with him- but the cancer spread and we lost him. Again if he'd been screened he maybe could have been saved.

Discussion comment:

My nan was 65 when her lung was removed. Screening must begin from 50 – 55

Recommendation comment:

It should be- deaths from lung cancer and people diminished qualities of life could be stopped. Not all lung cancers are caused by smoking – there is a miss conception that only smokers get lung cancer – this is not true and therefore people should be screened

25. **xxxx xxxx Member of the Public**

Affected Comment:

I lost my dad to lung cancer 5 months ago. My dad was a very fit and healthy 78 year old who had never smoked in his life, had always try to remain active with going to the gym and in more recent years doing walks. He was still doing long walks and playing on the floor with his grandson 4 months before he died. He started getting back pain which over a few weeks began affecting his legs but for weeks no GP would see him and just told him its what happens in old age and to just take some pain killers and have some physio. He deteriorated further and we took him to 111 emergency appointment and to A&e but nobody made any effort to do any scans to find out what was causing his symptoms, he was sent home with pain killers. Once he lost bowel and bladder control he became a medical emergency so we took him back to A&E and they finally did scans which revealed he had a tumour on his spine. But this was his secondary cancer as it had spread from his lung and was now in his bones. We were told there was nothing they could do for him and he may only have up to 2-3 months to live. He died within a month of this diagnosis. My dad had begged to see his GP for nearly 2 months as he felt it wasn't just normal backache and that he was struggling to walk and even sleep at night due to the pain he was in but he was severely let down. He should have been seen and referred for a scan to get to the bottom of what was causing his sypmtoms that were getting worse and not responding to the treatment he was having at that time.

Discussion comment:

I feel that screening shouldn't be limited to just smokers and a limited age bracket. Anyone can develop lung cancer whether they are a smoker or not and it also isnt just limited to people between 55 and 75. What about all these people under 55 that are being diagnosed with lung cancer? Some of them at stage 4? What about all these people that have never smoked being diagnosed with lung cancer again at stage 4 and wont get it picked up in time for effective treatment all because they are deemed as not as much at risk? And what about all these people that are over 75, do we just let them die without a chance just beacuse they are older? Surely if anyone can develop lung cancer then we need to have a screening programme that is for everyone as lung cancer doesn't discriminate.

Recommendation comment:

I think screening should be recommended and not be restricted to just smokers or a particular age group as the statistics show that anyone can get it and too many are dying all beacuse it was caught too late.

Alternatives comment:

I feel that more needs to be done at GP level. There should be a cancer specialist in every GP surgery that can at least refer for urgent scans or do blood tests to help diagnose sooner. GP's need to stop treating

symptoms with tablets and actually refer and do tests to find out the cause of these symptoms. People shouldn't have to beg to be treated or made to feel like they don't matter and are not entitled to treatment.

26. xxxx xxxx Member of the Public

Affected Comment:

I lost my Dad Christmas day last year to lung cancer. He had chest xrays after several lots of antibiotics being treated for chest infections. There needs to be a quick screening that can pick it up eithii6 all this editing and mistreatment. He had to wait too long for surgery that on the day they couldnt operate due to spreading. Things need a faster response

Evidence Comment:

Evidence was missed in xrays it was only the 2nd xray that they found something

Recommendation comment:

Screening should absolutely be recommended

Alternatives comment:

Faster response to diagnosis, gp being more aware that a prolonged cough needed urgent investigations you many times antibiotics are issued

27. xxxx xxxx Member of the Public

Affected Comment:

My friend has lung cancer (45) she was a non smoker. More screening is needed for cancer. Screening saves lives and saves the NHS money in the long run. Treating stage 1&2 cancer is less expensive than 3&4.

28. xxxx xxxx Member of the Public

Affected Comment:

This condition has affected me. I had breast cancer in 2017 which spread to my lymph nodes. On a routine examination in 2021 with my consultant I told her I had arm pain so she asked for a scan, they found I had a 8mm nodule on my lung which is growing. We all no once you have cancer it will likely return somewhere else. If it wasn't for me saying about a random pain in my arm I would not of had a scan and the nodule wouldn't of been found. I still don't no my outcome yet as I need another scan, my nodule is 9 mm now and not looking good, why can't any treatment be done quicker instead of waiting to see how big it grows, it's not fair on me or my family. Things need to change.

Discussion comment:

The sooner patients can be screened after having cancer and not just waiting to see if it happens the better because I wouldn't be where I am now, waiting and seeing!!!!

Recommendation comment:

Definitely should be recommended as having cancer once you no it's coming back and a lot of the time in the lung

Alternatives comment:

Listen to people who have already had cancer, we no our bodies and no when something isn't right, you don't always get heard until it's too late

29. xxxx xxxx Member of the Public

Affected Comment:

Yes, my best friend died of cancer

Recommendation comment:

It must be considered to allow earlier detection

30. xxxx xxxx Member of the Public

Affected Comment:

We have family and friends who have been negatively affected by lung cancer diagnosis in the later stages. Earlier diagnosis would have greatly improved their chances of survival.

Evidence Comment:

No

Discussion comment:

I just feel that a screening programme could help so many people to find a diagnosis early and then hopefully prevent death. Also this would reduce the impact upon the NHS by supporting treatment early on rather than battling through end of life care.

Recommendation comment:

Screening should be recommended, it can only bring positive results to help the impacts of cancer. We should be using the technologies and medicine available to us to save every life possible and early detection is key. I do not see any argument not to screen other than cost. A screening programme surly saves money in treatment long term if someone is diagnosed early.

Alternatives comment:

I think a regular screening programme as with breast cancer and smear tests is the most impactful way forward.

Other comments:

A more risk adverse assessment of symptoms by GP's..GP's are often quick to write off symptoms without exploring other options, caution must be applied where there is any risk in order to detect without a screening programme.

31. xxxx xxxx Member of the Public

Affected Comment:

My husband had lung cancer,he wasn't diagnosed untill he started to cough up blood,he had chemotherapy and radiotherapy but his diagnosis was too late!!!!

32. xxxx xxxx Member of the Public

Affected Comment:

I really do think that any screening that exists for any cancers should be available to all. The cervical screening has saved many many lives.

My aunt died from lung cancer she was diagnosed at stage 4, who knows what would have happened if it was found earlier via screening.

33. xxxx xxxx Member of the Public

Affected Comment:

My Dad was diagnosed with lung cancer in October 2015 after attending the doctor for six months – showing all the classic signs. His lung was removed in November 2015 and he had treatment and was back to work the following May 2016. In the October again he experienced rib pain and the doctor said he had a broken rib, it turned out his cancer came back and had spread to his bones. He was due to start a clinical trial but due to an infection he was too ill and died in April 2017 age 64. If my dad had been screened in really believe he would of had a chance of living so much longer. We have a huge hole in our lives and I would love to see lung cancer screening so other families are spared.

Recommendation comment:

Absolutely should be recommended!

Alternatives comment:

Quicker diagnosis – 6 months my dad attended his GP before diagnosis!!

34. xxxx xxxx Member of the Public

Affected Comment:

My previous husband passed away from lung cancer at 43 as it was found to late, it would have been a blessing to have had the screening opportunity and perhaps save a life.....

Recommendation comment:

It should be a must like breast cancer screening... it's a curable disease if caught early....

35. xxxx xxxx Member of the Public

Affected Comment:

Yes. My mother wasn't diagnosed until she had stage 4 lung cancer. She didn't stand a chance. She was shocked and had so much still to live for and look forward to. She died 16 weeks after diagnosis No specific comments

Discussion comment:

None specific

Recommendation comment:

Screening should be recommended

Alternatives comment:

Doctors to see everyone over 70 every six months for full MOT

Other comments:

None

36. xxxx xxxx Member of the Public

Affected Comment:

Please start screening for lung cancer as it will help save lives

37. xxxx xxxx Member of the Public

Affected Comment:

Yes. My father died from lung cancer.

Recommendation comment:

I think it should be recommended, if it can detect lung cancer sooner. Similarly to breast cancer screening.

38. xxxx xxxx Member of the Public

Affected Comment:

My husband died of lung cancer 12 months ago.

Evidence Comment:

My husband went to his dr as he had pain in his chest when he exerted himself. He was told his symptoms were not bad enough to be referred. 2years later symptoms were worse. They decided to put him on the waiting list for a heart scan and possible stent.

A years wait for a scan. So many times we returned. He told the dr he felt differant from when he had chest pain previously and xxxx had a stent fitted. We kept returning being told there was a years wait for a stent. I recorded him one day as we walked. He walked for 1minute 8 seconds before hanging over a fence gasping. We returned once again and luckily saw a differant dr who sent him for an x-ray. 3 years since he had 1st gone to the drs he was diagnosed with lung cancer. By this time it was in both lungs, pelvis, prostate.

The treatment he endured absolutely destroyed him. It was so severe it breaks my heart when I think of the state he was in the entire time. What a way to spend your final year together.

If there was screening this would of been picked up so much earlier sparing him so much suffering and not destroying my life alongside it. My life will never be the same. The care he had from all departments of the hospital was incredible. The hospice and hospice at home were incredible.

But he should never of died. He should of been diagnosed much earlier. Dr's in our surgery have allotted 10 minute consultation times for patients. It's no wonder so many people are not diagnosed.

Recommendation comment:

It should be recommended. Many people would be diagnosed early. Many would be cured and not have to endure such severe treatment.

Alternatives comment:

Get Drs to listen to their patients. We know our own bodies. We have gut feelings.

39. xxxx xxxx Member of the Public

Affected Comment:

My father in law, my father both died of lung cancer and my mum is now palliative care with terminal lung cancer.

I am 48 with a history of smoking gave up 15 years ago.

Screening is my only way of monitoring my lung health, I am not eligible for another seven years if I live in an area offering screening to be assessed and with symptoms being vague or non existent in stage one or two my chances of receiving curative treatment are very low.

I am checked for breast, why not lung? Surely screening is cheaper than treatment and care costs.

Lung cancer has devastated my family, and nhs further counselling and medical costs through dealing with the shock that someone appearing healthy, active, can be dead in weeks following a diagnosis

Evidence Comment:

It's out of date, there is clear evidence from the lung health check by NHS england

Alternatives comment:

They can't early detection is the only way

40. xxxx xxxx Member of the Public

Affected Comment:

I have been diagnosed with Stage 4 NSCLC in March 2020. Had I have been screened, I potentially would have been diagnosed as Stage 1, had an operation and be in remission, costing the UK and the NHS much less money per year. I have 2 scans every 3 months now, MRI and CT scans, medication costing thousands of pounds every year. The cost of screening would be far less to the country then the cost of treating this disease. This is no longer a smokers disease, it's getting more common in woman in their 20's, the stigma associated with being old and a smoker has probably prevented investment into this cancer, it's almost like we deserve it and did it to ourselves, but we would never say that to a bowel cancer patient because they ate meat!

Screening will save lives and save the NHS money fill stop.

Discussion comment:

Screening will save lives and save the NHS money fill stop.

Recommendation comment:

Screening will save lives and save the NHS money fill stop.

41. xxxx xxxx Member of the Public

Affected Comment:

Friends

Recommendation comment:

Yes they should

42. xxxx xxxx Member of the Public

Affected Comment:

Friend's mum died of only 3 months after diagnosis... screening could have saved her life

Recommendation comment:

Yes, prevent further deaths

43. xxxx xxxx Member of the Public

Affected Comment:

I believe screening for Lung cancer is of paramount importance to the scottish public.

44. xxxx xxxx Member of the Public

Affected Comment:

My mother died of Lung cancer 3 months after diagnosis. Palliative care was the only offer due to the late diagnosis – early screening may have picked this up earlier to give her a better chance of surviving and quality of life.

My close friend was only 37 when she was diagnosed, a young mother and wife who died at 40. At the time she was told it was likely that she had had it for 5 years before it was detected.

Not only could screening detect it earlier, it also would have the potential to stop it from spreading or metastasising as happened with both my mother and friend due to early treatment.

Recommendation comment:

Should be recommended 100%

Alternatives comment:

Lung cancers have a low survival rate, and one of the least funded areas. It has been proven in other areas, that funded research and creation of drugs can improve the outcome for people. Extended supported by the Government into specific targeted research should increase.

Other comments:

The focus was on smokers or former smokers as target areas – whilst I appreciate this in the people I knew – my mother stopped smoking 30 years previous and my friend never smoked, but did cycle around busy traffic filled city. This may be the first step, but do not overlook that this is not the only cause and if this is successful, it should be considered for wider rollout to non-smokers.

45. xxxx xxxx Member of the Public

Affected Comment:

My mother died from lung cancer at the age of 69. She had a quick diagnosis to death of 12 weeks, the diagnosis of her lung cancer only being due to symptoms of her metastasised brain cancer (neurological) which discovered the brain cancer and then after further investigation discovered the lung cancer. She had absolutely no lung cancer symptoms.

She was not a smoker, although may have had the partial cigarette when younger, but was also a strong passive smoker. She was an air stewardess for many years and she was working full time on the planes when smoking was allowed, and would therefore be passive smoking on long haul flights so may as well been a heavy smoker.

If this screening was available there's a possibility she would've been screened, the cancer found early and therefore a chance of surviving like many other cancer survivors of other types of cancer.

Recommendation comment:

The death rate is so high in lung cancer as large as breast, colon and prostate combined. The reason it is so high is due to late diagnosis due to no symptoms. Screening would prevent deaths and I'm sure make many peoples lung cancer treatable.

46. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with stage 3 lung cancer in 2020

Recommendation comment:

I think screening should be recommended for everyone as the earlier the diagnosis the faster treatment commences and the better the outcome of a full cure.

Alternatives comment:

The medical care I received has been faultless, but every city should have access to this machine.

47. xxxx xxxx Member of the Public

Affected Comment:

Yes

Evidence Comment:

When will screening be carried out in Wales

Discussion comment:

When will lung cancer screening be available in Wales

Recommendation comment:

Yes it should especially in areas of health inequality

Alternatives comment:

Education

48. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with Stage IV lung cancer in July 2016. My diagnosis has not just affected my husband and I but also our respective children and particularly the relationship I had with my grandchildren, which has changed beyond recognition. I can't be the grandmother I used to be.

Recommendation comment:

I consider that screening is recommended. In the winters of 2010,2011 and 2012, I had a cough which was so bad I would end up retching and had to sleep upright in bed. Each time I was prescribed steroids and after a couple of weeks the cough went. The final time I saw the doctor, he said that if it didn't go with the steroids, he would refer me for a scan. I didn't have a scan but four years later I was diagnosed with lung cancer and my consultant told me I had had it for a number of years. I believe it would have been picked up sooner and perhaps at a stage when it was curative.

Alternatives comment:

Due to the increasing number of people being diagnosed but who had never smoked, I don't believe any pre-screening screening would be effective.

Other comments:

Recommendation to include everyone including non-smokers and those who have cancer/lung cancer in their family history.

49. xxxx xxxx Member of the Public

Affected Comment:

My mother had a CT scan for her lungs when she happened to be passing the Sports Centre car park, xxxx xxxx, as she was 70+ and an ex smoker. My Mum did not have any symptoms but this screening went on to prolong, if not, save her life. She had a 4 x 4cm LLL tumour that was completely removed 3 weeks ago. I 100% think that there should be lung screening programmes available in the UK and that it would save many lives.

50. xxxx xxxx Member of the Public

Affected Comment:

My late wife was fit and strong, did not smoke and showed none of the symptoms of lung cancer. She felt something was wrong but certainly not a lung problem. After a number of visits to the GP, a new one sent her for x rays. This showed stage 4 lung cancer. She lost a three year battle at the age of 57.

AS a person who who had regular checks for

Breast and cervical cancer, she would certainly have had regular chest x rays had they been available and could have been alive today.

Recommendation comment:

Had screening been available, my wife's condition would almost certainly have been picked up before it was too late.

Alternatives comment:

If a person has chest problems which persist, they will be sent rfor an x Ray as a matter of routine. Routine screening will save lives and I don't understand why it is still being debated.

51. xxxx xxxx Member of the Public

Affected Comment:

Lung Cancer killed my grandfather when I was very young, I remember it blindsided our family. I believe early detection could of helped prolong my grandfathers life.

Evidence Comment:

I have no comments.

Discussion comment:

I believe early detection/screening should be mandated across the UK.

Recommendation comment:

It should be, 100%!!

Screening programs has and will save lives.

Alternatives comment:

screening seems like the best option.

Other comments:

No

52. xxxx xxxx Member of the Public

Affected Comment:

My husband died from lung cancer in 2017

Discussion comment:

any screening is valuable and should be offered to many more people than currently

Recommendation comment:

I think it should be recommended, as too many lung camcers are found when it is too late for any treatment

53. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with non small cell lung cancer in my left upper lobe in December 2021. The presence of an encapsulated tumour was highlighted when I was admitted to Cramlington Hospital with Covid 19 and a chest x-ray was performed. Subsequent CT, Pet CT and CT guided biopsy confirmed that I had T2a N0M0 adenocarcinoma. Happily the tumour was completely removed and lymph node dissection at surgery has since confirmed no spread to lymph nodes proximal to the tumorous lung. Had I not had that x-ray when in

hospital with Covid 19 I would have remained undiagnosed until at some point I would have become symptomatic and hopefully been able to convince a GP to refer me for tests. I am very sure that if that had been the case this cancer would likely have grown or worse, spread and my life would be severely cut short.

I am absolutely of the belief that lives can be saved if the NHS adopts routine checks on people who may be at risk of lung cancer. I was a smoker since age 18 but gave up in 2009. I had hoped I had dodged the bullet but at the age of 69 my unhealthy past habit caught up with me.

Evidence Comment:

I am pleased to see the suggested targeted screening for lung cancer in people aged 55 – 74 with a history of smoking. I am most fortunate to have had my lung cancer diagnosed at an early stage due to a chest x-ray for Covid 19. I want that other people should have the advantage of early diagnosis and to be treated with a high chance of removal of primary malignant tumour.

However, if the NHS is to find tumours at an earlier stage and offer appropriate treatment, then the NHS must be equipped in all respects to cope with what might be a significant increase in patients requiring various appointments as part of diagnosis and treatment.

I would also like to put in a word for expanding prehabilitation and investment in post lung surgery rehabilitation programmes nationally

54. xxxx xxxx Member of the Public

Affected Comment:

My mother died of small cell lung cancer last year.

Evidence Comment:

My mother died of small cell lung cancer last year. She was a never smoker. We were told 99% of small cell lung cancer patients smoke. Obviously not in my mums case. There is little treatment for small cell, so screening is very important. It spreads so fast, that most are already extensive when diagnosed.

Discussion comment:

Screening is needed for non smokers. Lung cancer is the often fatal and outcomes have not improved at the rate of other cancers.

Recommendation comment:

I have screening for breast cancer, cervical cancer, bowel cancer. At the daughter of a lung cancer victim I would like to have screening.

Alternatives comment:

There needs to be more research into small cell lung cancer.

55. xxxx xxxx Member of the Public

Affected Comment:

Lung cancer killed my athletic 60yo non smoking mother just as she became a grandmother.

It rocked our community as she'd spent her whole life caring for others.

No symptoms at all. A stroke and 15 months later she was dead.

She was the picture of health.

Recommendation comment:

I've read about the screening program done by Wythenshawe and heard of early detection.

56. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with lung cancer during lockdown..

No symptoms other than a cough that doctor thought was after effects of covid.

Sent me for a chest X-ray to put my mind at rest and turned out I have Nslc. Treatable not curable (Devistated)

SCREENING COULD SAVE LIVES!

Recommendation comment:

100% recommended! Could save many lives!

57. xxxx xxxx Member of the Public

Affected Comment:

My maternal great aunt died of lung cancer aged 59. My maternal grandfather died of lung cancer aged 73. My maternal grandmother died of lung cancer aged 87. And in August 2021 my mother died of lung cancer aged 64. All were non smokers. All were diagnosed at stage 4. All, apart from my 87 year old grandmother, had some treatments that failed to save their lives.

Discussion comment:

Lung Cancer is a condition with a high mortality rate due to very often remaining undetected until it is in the advanced stages. Yet, when detected in its early stages it has a very high survival rate. A national screening programme would not only save hundreds of thousands of lives, but save money on aggressive treatments needed for advanced stage lung cancer, by detecting and treating cancers earlier.

Recommendation comment:

Lung Cancer is a condition with a high mortality rate due to very often remaining undetected until it is in the advanced stages. Yet, when detected in its early stages it has a very high survival rate. A national screening programme would not only save hundreds of thousands of lives, but save money on aggressive treatments needed for advanced stage lung cancer, by detecting and treating cancers earlier.

Alternatives comment:

Screening people with a family history

Other comments:

Screen families with a strong family history

58. xxxx xxxx Member of the Public

Affected Comment:

This terrible condition claimed the life of my Mom. How quickly it took her was beyond belief. If she had screening then it would have been found sooner. She had no symptoms until 2 months before. More needs

to be done as it is one of the biggest killers in the UK. How else are we meant to find it if people don't have symptoms?

It took my Mom's life and she really had a lot of life to live, to see her family grow up-grandchildren-who she adored. It robbed me of my best friend. No one should have to go through the suffering she did.

Recommendation comment:

Definitely. How else will you find it when a lot of people don't have symptoms?

Alternatives comment:

Finding it early. Blood tests,screening and yearly checks.

Other comments:

Work needs to progress quicker on the cancer blood tests. Cancer is so common now, more needs to be done. It's worse than covid. We have got a vaccine for this in a year so,with all the money pumped into cancer charities,why are we now worse off?! It doesn't make sense.

59. xxxx xxxx Member of the Public

Affected Comment:

Hello,

I was diagnosed with stage 1 lung cancer that was successfully treated.

I feel that I was lucky to have had it diagnosed early, but also only because I am a health professional. I did not have specific symptoms, and almost ignored them.

Lung screening would help pick up more cancers early and hopefully would have a similar outcome to me.

60. xxxx xxxx Member of the Public

Affected Comment:

My mum is lying at the side of me as I type this and is dying from lung cancer. She was diagnosed in July 2021 with stage 4 lung cancer and started treatment almost immediately. The doctor said she had probably had it for 3 years and that he had spread to her adrenal gland. It has now spread to her brain. If screening had been in place it would have been picked up much sooner and she would have had a chance to beat it. My mum will not get that chance but please give that chance to others families. We are heartbroken.

Recommendation comment:

As I have stated above my mum is dying from lung cancer that the doctor believed she had had for 3 years already when she was diagnosed. If screening had been in place my mum could have been treated much quicker and therefore could have survived this terrible disease.

I strongly believe that screening should be in place, it won't help my family but would help so many others to receive the treatment they need early and therefore have a much greater chance of survival.

Alternatives comment:

To make GPs much more aware of the need to send people for chest X-rays if they have symptoms of lung cancer. My mum was sent away on many occasions and after her diagnosis we looked into this as a family and she should have been sent for a X-ray the first time she went. We were not aware of this until she had been diagnosed and we started to look into it.

61. xxxx xxxx Member of the Public

Affected Comment:

My husband was diagnosed with stage 3 lung cancer 7 years ago after months being told it was chest infection he died 9 months later at the age of 57 his dad also died at the age 53 also with lung cancer this machine would be a big help to get it early and save life's please say yes to the machine don't let people suffer

Recommendation comment:

100% you should have lung cancer screening

62. xxxx xxxx Member of the Public

Affected Comment:

My dad died of lung cancer at only 68 years old. My father in law died of lung cancer 9 months later when he was only 65.

Evidence Comment:

Recommendations from 2007 are outdated. Clinical trials into screening for lung cancer is the way forward to prove how effective it really is in saving lives. Screening for lung cancer could catch lung cancers in the early stages well before symptoms start showing. This could save so many lives.

Recommendation comment:

Yes I definitely think screening should be recommended. It could potentially catch cancers in the early stages before people start showing symptoms. When caught in the earlier stages, there are many more treatment options which improves outcomes.

Alternatives comment:

Banning selling cigarettes like they are currently bringing in in New Zealand is another way to help decrease the incidence of lung cancer.

63. xxxx xxxx Member of the Public

Affected Comment:

My mum was diagnosed with Lung Cancer stage 4, age 63, she was fit healthy and did not smoke, the oncologist said that they think she had it for 3 years with no symptoms before being picked up at stage 4 when symptoms started, we lost her last month after a 3 year fight, mostly miserable for her especially when covid hit! More needs done to screen for this terrible disease, what my mum endured and all our family has endured for 3 years is simply unacceptable and we have been robbed of our mum and been dragged through hell! Had she been screened this would have been caught earlier with most likely a better outcome! Screening needs to start now !

Recommendation comment:

It should be recommend straight away in my opinion

Alternatives comment:

There could also be quicker response times and communication should be a lot better, letter process is diabolical with my mum missing appointments because she simply did not receive the letters that were allegedly sent out

64. xxxx xxxx Member of the Public

Affected Comment:

I lost my nan from lung cancer.

It was heartbreaking for all of her family

The most upsetting part is it was caught just a little too late

If this had been picked up only months prior it would have been confined and the operation to remove successful.

Screening would mean people were diagnosed earlier and hopefully this will stop people losing their loved ones to this horrible disease

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

Yes to get earlier diagnosis

65. xxxx xxxx Member of the Public

Affected Comment:

My beloved sister died in May 2013 after being diagnosed with lung cancer in August 2012. The cancer spread to her brain and finally to her bones. My sister was already at stage four when the cancer was confirmed. I am a great believer in scanning for any diseases if it helps towards an earlier diagnosis and therefore possible treatments might provide a better outcome.

Evidence Comment:

I do not have medical or scientific knowledge so do not feel able to comment

Discussion comment:

No

Recommendation comment:

I think screening should be recommended. Anything that can assist an earlier diagnosis can only be of benefit.

Alternatives comment:

I think the time it takes from an initial GP consultation to obtaining a referral to the appropriate consultant for further investigations takes too long. I read of many instances where patients are seen repeatedly by their GP before lung cancer is considered. Perhaps a different pathway is necessary for GPs whereby lung

cancer is considered first rather than seemingly last in their diagnosis. The availability of access to a suitably structured screening process would help this

Other comments:

Lung cancer needs to be brought much more into the public eye than it currently is. I think unfortunately many people associate this disease with smoking and drinking and it doesn't get the attention it deserves. Lung cancer seems to be more prevalent in younger, fitter non smokers now and in fact can affect anyone irrespective of their lifestyle.

Education is the key as has happened with breast and prostate cancer

66. [REDACTED] Member of the Public

Affected Comment:

In the 1990s I was involved in the establishment of a Lung Cancer service at what is now the Liverpool Heart and Lung Hospital

As an employee of the hospital in the computer area, I was frequently telephoned by family members who were affected by others being diagnosed just because I was working late and someone for them to talk to.

Later at a conference in Manchester because I was not medically qualified, my suggestion that we all knew someone with a persistent cough that should consult their GP. was not accepted, but I was glad to see a London Bus carrying the slogan some years later.

I was involved with the development of computer software which was used in theatre diagnostics to incorporate medical records

Evidence Comment:

No Comments

Discussion comment:

No Comments other than How do you gain the confidence of individuals as the prognosis is so poor.

Recommendation comment:

I do not think screening is an improvement. Better to improve access to treatment and publicise early symptoms

Alternatives comment:

Better to improve access to treatment and publicise early symptoms

Other comments:

Introduce support for affected families and friends

67. [REDACTED] Member of the Public

Affected Comment:

My father died in Jan 22 of secondary lung cancer. I am also a band 8 healthcare professional. So many working class people work and live in environments where prolonged, repeated exposure to particles are inevitable also smoking was a part of many of my generations 20s. And 30s there simply must be national

lung screening screening program for all 50plus with blood screening for markers. Covid has increased the urgency of this with clear pattern of long term lung damage we should be monitoring and understanding.

Recommendation comment:

As above yes I do it should be risk based at younger ages and expanded as people reach 60-70

Alternatives comment:

Focusing on early market detection which I assume would be via screening

68. xxxx xxxx Member of the Public

Affected Comment:

My sister died with lung cancer that was diagnosed too late. I think there should be mandatory tests every 3 years from age 55 for lung cancer. And more ads on television about the issue of the continuous cough, saying that it can be just a gentle cough you would not necessarily notice. People need to take notice of it and get it checked out. There should also be continuous advertising and public health messages not to smoke, and for ex smokers to keep getting themselves tested.

Recommendation comment:

Screening should be recommended

Alternatives comment:

I am interested in before people are diagnosed. Increasing the number of people who present for screening. The information that early diagnosis can save your life

Other comments:

Public health messages on television should be implemented.

Programmes also that provide detailed information on what happens with early diagnosis to stop people being scared.

69. xxxx xxxx Member of the Public

Affected Comment:

My mother died from lung cancer in 2015. It was not caught early enough and so when she was diagnosed she was stage 4.

Recommendation comment:

Yes, it could hav4 saved my mum's life.

Alternatives comment:

Better GP training. My mum was originally misdiagnosed.

70. xxxx xxxx Member of the Public

Affected Comment:

My mum had lung cancer – only diagnosed at stage 4 in July 2021.

My mum died today.

Evidence Comment:

Detecting lung cancer happens far too late – given there are very little symptoms.

Discussion comment:

Early detection where there are no symptoms saves lives.

Recommendation comment:

Early detection where there are no symptoms saves lives. It's should be recommended. My mum was 69 last week and was in good health until diagnosis at stage 4.

What is the matter with people who think this isn't a good idea?!

71. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with stage 4 NSCLC. I didn't have any symptoms at all. If I could have had screening I may have found out earlier and had a better prognosis. I am currently stable, due to immunotherapy treatment. This won't help me now, but could help so many people in the future, as early diagnosis can mean a cure via surgery.

Evidence Comment:

I hope that the age limit will be lowered and offered to many people not just smokers or former smokers Lung cancer is on the increase especially in younger women

Recommendation comment:

Screening should definitely be recommended As with Breast cancer, prostate and cervical cancer, early detection saves lives.

Alternatives comment:

More funding needs to go towards research into Lung cancer as this is the 2nd biggest killer

72. xxxx xxxx Member of the Public

Affected Comment:

My mother and grandfather both died from Lung Cancer.

My mother died last September at 64 after bravely dealing with the disease for 3 years. It was a rare mutation type lung cancer of EGFR. My mother had last smoked as a girl of twenty so had given up over forty years ago.

Her father, my grandfather, died ten years ago, at age 80.

Recommendation comment:

I think screening should definitely be recommended. It's vital to catch this dreadful cancer early. My mother's cancer was discovered too late at stage 4. Early diagnosis is crucial and I think screening should be given to those of a younger patient whom have lost a close relative to lung cancer.

Alternatives comment:

More research needs to be funded so that the genetic makeup of the lung cancer tumours can easily and quickly identified. The drugs that can halt the growth of lung tumours need to become readily available, and surgery techniques need to be fine tuned so that hard to access tumours (ie. Those close to the heart) can be operated on.

73. xxxx xxxx Member of the Public

Affected Comment:

I lost my father to lung cancer (non small cell). Without doubt, if his lung cancer had been picked up earlier, we would have had much longer with him as preventative treatment could have happened. It's the no 1 killer of men in this country. If that's the case, why is there breast and bowel and prostate screening but not lung?

It is a horrible and devastating disease. Please make this a National screening programme soonest

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

100% should be. It's the biggest killer of men and third biggest cancer killer in this country.

Pollution is at record levels and so many people are getting cancer as a result of that. If breast and bowel are screened, then lung cancer most definitely should be too

Alternatives comment:

Easy prevention by screening = less drugs and treatment needed which = less expenditure. M the NHS should focus more on preventative rather than reactive medicine to treat in the moment but not necessarily cure.

74. xxxx xxxx Member of the Public

Affected Comment:

I have lung cancer

Evidence Comment:

I waited too long for. Chest X-ray due to the Drs surgery being closed.,like so many others,

Recommendation comment:

It should be recommended

It would save so many lives being diagnosed early..

Alternatives comment:

Get GPS to open as pre pandemic.

75. xxxx xxxx Member of the Public

Affected Comment:

Diagnosed with Stage IV NSCLC with brain and adrenal mets 2018 age 64. Previous smoker gave up 20 yrs previously.

Evidence Comment:

Lack of uptake by current smokers who believe 'too late' needs education programme e.g. my father smoked from a very young age till his death and didn't develop cancer so definitely worth being screened.

Discussion comment:

I would be really keen to see screening introduced, am previous smoker gave up nearly 20 yrs prior to diagnosis. My only symptom was a moderate cough and I was already stage IV with mets and cannot be 'cured'. If I had the opportunity to be screened may have been found so much earlier.

Recommendation comment:

Definitely think it should be introduced – majority of patients in my treatment group were diagnosed at stage III and IV. Prognosis would be much better if found earlier.

Alternatives comment:

Education on symptoms and importance of getting them checked out – dread to think how many undiagnosed cases there are due to pandemic – everyone assumed cough etc would be COVID – all cancers will have suffered greatly over the last two years.

76. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed Stage 3 Lung cancer after coughing up 2 blood clots and going through Accident & Emergency.

With hindsight I had many symptoms that were not picked up by my GP and Practice Nurses due to my underlying fitness levels (ex Forces).

Evidence Comment:

This states that smoking is the biggest cause of lung cancer, however there is evidence that more and more lung cancers are being diagnosed in none smokers with no history.

These comments stigmatise lung cancer.

Discussion comment:

I believe that lung cancer diagnosis at a late stage has major impacts across the health pathway for the NHS, the patient and those close to the patient.

The cost to treat and cure late diagnosis and cost of end of life care, far exceed the cost of treatment of an early diagnosis.

Obviously if a patient is diagnosed at a late stage and prognosis is not good, the impact upon that individual and those close to them, carers, loved ones, friends and family are all impacted.

Secondary illnesses also need to be treated and the cost impact to the NHS is huge and maybe lifelong such as Pulmonary Embolisms with lifelong treatment of Rivaroxaban – these secondary illnesses should also be accounted for.

Recommendation comment:

A National Screening programme should be adopted for lung cancer.

As the second biggest cancer in the U.K. (as per this site) when there are National Programmes for: Cervical, Breast, Prostate and Bowel cancers and yet nothing for Lung Cancer this is a huge imbalance and the stigmatise linking smoking to lung cancer has contributed to this lack of a screening programme

Alternatives comment:

I do not accept that there is an alternative.

Smoking cessation clinics have delivered a reduction in smokers, the price of cigarettes has increased and yet lung cancer is not reducing by the same levels, with many never smokers and younger people being diagnosed at stage 3 and stage 4.

Other comments:

I would like to see NHS, Charities and the commercial sector (Siemens for example) joining forces to raise awareness and roll out and deliver a National Standardised Lung Cancer Screening Programme

77. xxxx xxxx Member of the Public

Affected Comment:

No

Discussion comment:

I see there could be some negative effects of the screening so could the screening be optional ?

Recommendation comment:

Yes I think the screening should be recommended as it most likely would improve the quality life of people who were diagnosed with lung cancer or any other lung condition established as they would be treated earlier than without screening.

Perhaps also need to consider that people in the age range 55-74 were not aware the dangers of smoking as is the case with younger generations.

I would brought up with 2 parents that smoked 20-40 a day and at the time it was deemed ok to smoke. Hopefully the program would only need to last for a generation as there are less and less smokers each year in younger generations.

Alternatives comment:

Smoking cessation services could be extended to support people for longer. Currently the service local to me is restricted to 8 weeks support so if you do not quit then you are on your own again.

Other comments:

Could the screening be available privately with patient paying for the actual screening / diagnosis then obtaining treatment from NHS ?

I would happily pay for the screening but know I could not afford the actual cancer treatment.

78. xxxx xxxx Member of the Public

Affected Comment:

I do know people who have been affected by this terrible disease and as its the second most common cancer I think there should be a national screening programme.

79. xxxx xxxx Member of the Public

Affected Comment:

I grew up with both parents and uncles smoking heavily in the house. My memories where of clouds of smoke filled rooms. Clothes that smelt of smoke.

I am not and never have been a smoker yet I suffer from asthma and bronchitis. I have always been into sport and kept myself active.

We know the dangers of passive smoke but as children growing up in these conditions we have no choice but to inhale and absorb the toxic substance. We didnt have a choice. We are not considered, because we dont smoke, to be in the dangerous category yet people who have never smoked get lung cancer – did they grow up in a smokey environment? Roy castle didnt smoke but played in smokey environments this should be the focus of the study – the dangers of passive smoking, of growing up with parents that smoked, screening and supporting those that didnt have a choice and suffer from lung conditions that are linked to passive smoking.

I feel the conditions we grew up in have had a huge impact on my siblings and my health. My sister died age 64 pulmonary embolism, my eldest brother age 63 recovering from mouth cancer (he smokes) my 2nd eldest brother currently on blood thinners due to clots and he suffers from constant clearing of chest and me asthma and bronchitis. Surely there is a connection? Non smokers but passive smokers are the forgotten victims!!

Recommendation comment:

Screening should be recommended so that cancers and other lung conditions are caught earlier enough so that something can be done to prevent it from causing long term or even terminal conditions that in turn put a lot of pressure, time and money on the NHS.

Screening should also be extended to those who grew up in smokey homes.

Alternatives comment:

Education is vital from an early age. Workshops introduced into schools to educate at each stage (primary, secondary) on the dangers, impact on health initially and later in life. Solutions given to those growing up in households whereby parents smoke, what they can do to help themselves, to reduce passive smoking.

Other comments:

Education with all its gore is vital.

A study done of those growing up in smokey households.

Monitoring through life of those who grew up in smokey house holds.

For those that do smoke, provide education on what the toxins in the tobacco does to the body. Help with stopping smoking. If people carry on smoking whilst being cared for should be made to pay for treatment or eliminated from a care plan because if they are not willing to help themselves no support in the world will change them.

80. xxxx xxxx Member of the Public

Affected Comment:

I have recently been diagnosed with stage 3 lung cancer that is inoperable. As an ex-smoker who gave up 9 years ago I had assumed that I need no longer worry about lung cancer and I certainly had no symptoms until just before Christmas 2021 when I developed a cough and then began to feel breathless when exercising. I contacted my GP in January and was referred for a chest x-ray in early February. The results clearly indicated a problem and I was quickly sent for a CT scan which then confirmed the diagnosis. My sister who lives in xxxx xxxx has for a number of years been referred for x-rays as she lives in an area

where the targeted screening is being trialled. Had I been fortunate to also live in an area which was also trialling the targeted screening I believe it is very likely my cancer would have been detected at a much early stage and surgery would have been an option which would likely have given me a much better outcome and longer life expectancy.

If this was a national screening programme I believe it would pick up many people like me and result in much earlier detection and consequently better outcomes.

Recommendation comment:

I think screening should very definitely be recommended.

81. xxxx xxxx Member of the Public

Affected Comment:

Yes my mum recently passed away with lung cancer having never smoked in her life and having a very healthy lifestyle.

Recommendation comment:

Yes as there are still so many misconceptions as to who may get lung cancer and screening would enable everyone to choose to be informed at the earliest opportunity which is obviously better in terms of outcomes.

Alternatives comment:

Better information and clarity that it is not necessarily a condition of smokers.

82. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with lung cancer at the age of 42. Otherwise fit and healthy with no symptoms and a lifelong non smoker. It was found by chance on an MRI of my neck undertaken to check disc issues. The early detection meant I was able to have surgery and I am currently 4 years cancer free. If it had not been detected at that point it is highly likely that I would not have been diagnosed until a much later stage with the accompanying much poorer prognosis and need for more costly treatments.

Evidence Comment:

It is possible to screen for lung cancer and the Roy Castle Lung Cancer Foundation have run trials of exactly that. The cost of screening and early detection. Would outweigh the cost of treatment at a later stage and save lives. There is strong evidence that early detection of lung cancer is critical to a better outcome.

Discussion comment:

Screening could save lives. Early stage lung cancer rarely is symptomatic so it is otherwise difficult to detect.

Recommendation comment:

Yes – see all my comments above.

Alternatives comment:

Better awareness from GPs – especially for potential cases in non smokers. And a public awareness campaign around risks and also symptoms (not just coughing) and the fact it can affect non smokers just as much.

Other comments:

Screening!!!!

83. **xxxx xxxx Member of the Public**

Affected Comment:

My mum died on March xxxx 2022 after a 2 year battle with lung cancer. Her cancer wasn't picked up until it was Stage 4, even though she was a smoker when younger. Doctors repeatedly gave her antibiotics for a 'chest infection' and she didn't like to keep going back and 'bothering them' when the antibiotics hadn't alleviated her symptoms. Had there been a screening process my mum may have been diagnosed a lot sooner than she was and her life could have been prolonged/successful treatment provided.

Discussion comment:

As lung cancer is a prevalent cancer in the UK it is imperative that a decent screening system is in place to reduce the numbers of people suffering and dying a very difficult and painful death. Education about the harm caused to lungs by smoking is also key.

Recommendation comment:

Absolutely should. The more people that can be identified early, the more treatment options are available. It makes sense.

84. **xxxx xxxx Member of the Public**

Affected Comment:

A friend

Discussion comment:

I think people should be routinely screened for all cancers because often it is too late at the time of diagnosis

Recommendation comment:

I think people should be routinely screened for all cancers because often it is too late at the time of diagnosis

Alternatives comment:

I think people should be routinely screened for all cancers because often it is too late at the time of diagnosis

Other comments:

I think people should be routinely screened for all cancers because often it is too late at the time of diagnosis

Also what had happened to the GP well man and well woman check ups? My husband had one at 40 (he is now 55) and I had one at 40 (I am now 50)

85. xxxx xxxx Member of the Public

Affected Comment:

My friend

Evidence Comment:

She went for an MRI for a completely different issue. Lung Cancer was found by chance as she did not have any symptoms. We screen breasts and cervix (smear tests) test for proatate etc why should lungs be any different? Silent cancers should be tested for. This would save hundreds of thousands of lives a year if not more.

Recommendation comment:

Yes, We screen breasts and cervix (smear tests) test for proatate etc why should lungs be any different? Silent cancers should be tested for. This would save hundreds of thousands of lives a year if not more.

Alternatives comment:

Put the money back into the NHS that us tax payers pay.

86. xxxx xxxx Member of the Public

Affected Comment:

My father was diagnosed with stage 4 lung cancer after being admitted to A&E with a suspected heart attack. He had no obvious symptoms, no cough and was a non smoker. He was only 71 when he died and 14 years on we miss him everyday. Screening could have saved him and given him a chance of seeing his grandchildren grow up, instead he died 3 months after being diagnosed.

Discussion comment:

This should be become a standard screening procedure to save lifes by early detection.Lung cancer has such a stigma, people ask if my dad smoked, he didn't but there is such ignorance about this biggest killer.

Recommendation comment:

Yes to save as many lives as possible and in turn save the nhs money

Alternatives comment:

If a blood test is available that would be extremely useful and life saving

87. xxxx xxxx Member of the Public

Affected Comment:

My Dad had stage 4C lung cancer with no previous symptoms. He fell ill 2 weeks before his diagnoses with what we all assumed was a cold.

If screening was in my place this could of been caught earlier and allowed my father to have treatment. Unfortunately he passed away within 5 months.

Recommendation comment:

Screening should be recommended to allow early detection.

88. xxxx xxxx Member of the Public

Affected Comment:

Yes; my father died of lung cancer when I was 14, and he was only 56.

Evidence Comment:

What's my father did die a long time ago, in 1990, I would very much hope that in the last 32 years, some progress could've been made towards earlier screening.

Discussion comment:

As above, I strongly wish for early screening for lung cancer so it can be treated early on and save more lives.

Recommendation comment:

Should be recommended- I have a friend who whose Lung cancer was only detected by screaming for something else entirely, and if it had not been caught, she could have been missed and lost her life. It was not detected in buying father until it was much too late either. Early screening is obviously keen to saving lives and give treatment.

Alternatives comment:

I'm not aware of alternatives. Perhaps a drive to educate the public as to what symptoms to look out for? Though sometimes there are no symptoms, and the symptoms only appear when it is too late. I think screening is the best answer.

89. xxxx xxxx Member of the Public

Affected Comment:

My Mum recently died of non smokers lung cancer. It was diagnosed after she had a cough that wouldn't go away. By the time it was diagnosed she had probably been living with it for years. I'm now scared for myself, my sisters and our children.

Recommendation comment:

I think a national screening programme would be so beneficial as people can live without symptoms for years and by the time they are diagnosed it is too late. With early screening for those at risk could have a huge impact on their life and those of their loved ones.

90. xxxx xxxx Member of the Public

Affected Comment:

I lost my mum and dad was lung cancer 2 years ago I would like to have the scan done to see if I have the condition as well so having this is important to me and my family for earlier diagnosis

91. xxxx xxxx Member of the Public

Affected Comment:

Yes my mother died from lung cancer.

Recommendation comment:

My mother despite her smoking habit was not screened for lung cancer. If she had been screened the cancer would have been picked up earlier.

92. [REDACTED] Member of the Public

Affected Comment:

I was diagnosed with Lung Cancer in 2011, and again in 2014. As I have been a lifetime non-smoker being diagnosed was a complete shock. Unfortunately the majority of people believe only smokers get Lung Cancer.

Evidence Comment:

In hindsight I believe my symptoms were dismissed due to the fact that I am a non-smoker. Screening may well have detected the condition earlier as I had been showing symptoms for a number of years.

Discussion comment:

Lung Cancer has a stigma of a “smokers disease” resulting in non-smokers with symptoms being ignored or dismissed. A national screening programme would help detect cases much sooner, particularly within groups who feel the disease won’t affect them.

Recommendation comment:

See previous comment.

Alternatives comment:

Far greater expenditure in awareness of symptoms, and highlighting the fact that the condition affects many people that are not smokers. The stigma associated with the disease needs to be removed.

Other comments:

See previous comments.

93. [REDACTED] Member of the Public

Affected Comment:

My Mum passed away from lung cancer [REDACTED] April 2020.. she was diagnosed in October 2019. I believe if there had been a targeted national screening service in our area we would have had longer with her as the cancer would have been picked up much earlier and therefore treatment more effective.

Recommendation comment:

Screening should be recommended as early detection will save lives.

94. [REDACTED] Member of the Public

Affected Comment:

My husband died two months ago with lung cancer. Had there been a screening programme he may have been told earlier and in time to do something about it.

Recommendation comment:

It should be recommended. It might have saved my husband.

95. xxxx xxxx Member of the Public

Affected Comment:

This condition has affected my family not once but twice. My own father and my father-in-law both had lung cancer and both died very quickly.

Evidence Comment:

Anything that can be done to test or investigate a lot more with speed that is being done now is important.

Recommendation comment:

Screening should be done, when you look at other forms of cancer they are found a lot earlier and treated with successful rates. Any screening that can help save life is important to the lives of everyone concerned whether family or the patient who get the lung cancer.

96. xxxx xxxx Member of the Public

Affected Comment:

We lost our 29year ol to lng cancer

Recommendation comment:

Having lost our son il think its essental that screening takes place.

97. xxxx xxxx Member of the Public

Affected Comment:

My dad died of lung cancer 6 years ago at the age of 55. He had attended doctors, walk in centres and eventually a&e where of it was not down to that one doctor doing a test he would have been fobbed off again, they told my dad he had anxiety, they said he'd be ok, they prescribed wrong medication, he was not okay he had small cell lung cancer and dies within 2 years of diagnosis. If screening was made available he could have had the help he needed earlier on and maybe he could have met his grandson maybe we could have had him for longer maybe he wouldn't have been misunderstand and ignored.

Recommendation comment:

If there is a legitimate reason not to have a screening process then I am all up for hearing that however I can only see the positives. There's is screening for breasts cancer, ultra sounds and smears for cervical. MRI for neurological etc etc why not a lung screening what is the reason?

98. xxxx xxxx Member of the Public

Affected Comment:

Yes, my Mum died of Lung Cancer last year. She was a non-smoker, a spritely, fit and healthy 69 year old. Her GP did not recognise her early symptoms and took 3 months to refer her. By the time she exhibited full

symptoms and was diagnosed her lung cancer was Stage IV metastatic. She suffered greatly through chemotherapy treatment and died 9 months after her diagnosis.

Evidence Comment:

The screening trial program that was carried out in xxxx xxxx (incidentally which is where I am from and where my Mum lived), demonstrated success in identifying people for referral and follow up, which allowed for successful early interventions. Screening should be for everyone, not just smokers. Had my Mum been screened her risk factors likely would have been spotted and her cancer could have been caught earlier.

Discussion comment:

Lung cancer is increasing among non-smokers and women, but for too long has been dismissed as a smokers' disease and this has been used to justify doing nothing to look for other causes and preventative solutions. Lung cancer often does not display symptoms until an advanced stage when it is untreatable. Therefore screening is imperative to catch it early when it is treatable.

Recommendation comment:

Yes, screening is the best option to catch lung cancer early when it is treatable. It should be available to everyone, in the same way as breast cancer and bowel cancer screening. Lung Cancer is the biggest cancer killer, and more should definitely be done to save lives. Screening could encompass not just CT scans, but there are blood tests and breath tests in development too... with funding and resources allocated, successful screening is achievable.

Alternatives comment:

In addition to developing and rolling out a proper screening test to everyone, GPs should be better educated to assess patients and spot symptoms early, and refer at risk candidates. My Mum suffered from bronchitis and chest infections for years, she also developed finger clubbing, diagnosed as rheumatoid arthritis. These are early risk factors for lung cancer – we didn't know because of lack of awareness.

Other comments:

Run National campaigns educating people about symptoms and urging them to get checked and screened, without only focusing on smoking. No one deserves lung cancer, not non-smokers and not smokers. Campaigns that only lecture people on giving up smoking to reduce their risk don't actually help anyone, and they especially don't help non-smokers who might be at risk of lung cancer for other reasons but wouldn't realise it or think to get checked.

99. xxxx xxxx Member of the Public

Affected Comment:

My mum was diagnosed with stage 4 lung cancer five years ago. We are so lucky she is still around and that prompt radiotherapy and chemotherapy stopped it progressing further and made it "dormant" however some areas are now showing growth. She stopped smoking before she was diagnosed. It is a cruel unforgiving disease and i know it will steal her from us soon. If a screening programme had been available, then maybe the outcome would be different. And i wouldnt be facing life without my mum. It could have been identified at stage 1 or 2 and treated successfully. This screening programme would save so many lives. I am so happy u are considering this

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

Yes. As i said above, it would save so many lives and identify early, cancers in the lungs, leading to more successful patient outcomes

Alternatives comment:

Mums treatment has been amazing and she is still with us. For now. I cant imagine a better alternative to the screening programme

Other comments:

No

100. xxxx xxxx Member of the Public

Affected Comment:

My mum was diagnosed with Lung Cancer in 2002, it was a late diagnoses and should have been picked up much sooner.

If screening was available at the time it may have had a better outcome for my mum & all of her family, 10 weeks after diagnoses my mum was dead.

My children robbed of their nan & my granddchildren robbed of meeting their great nan.

Recommendation comment:

Screening would pick up earlier detection of any changes / lung cancer giving a greater chance of survival. We all deserve the best chances in life and this would undoubtedly offer the maximum.

Alternatives comment:

When presenting with any symptoms which may indicate lung cancer, GPs should thoroughly investigate and offer checks with tests/etc not just diagnose asthma without having conclusive results first !

Other comments:

Many cases of lung cancer start with simple symptoms which can cover many an illness, but if symptoms persist it is imperative that follow up tests/ investigations are needed.

Save lives by early diagnoses !

101. xxxx xxxx Member of the Public

Affected Comment:

My husband died of lung cancer aged 56 after chemo a lovely man who loved life he had had oxygen at home but some people who suffering don't have this he had x ray at hospital was told it's COPD and to go back in a month for another X-ray he then suffered a collapsed lung it's heartbreaking.

Recommendation comment:

Shoul be recommended for early detection

Alternatives comment:

We had a cancer nurse but mainly left to cope on our own not much help for us more help is needed

102. xxxx xxxx Member of the Public

Affected Comment:

A lung cancer screening programme would save so many lives. My brother was only diagnosed at a very late stage. A screening programme at that time would have given him a greater chance of survival or a few more years with us. He was a non smoker and a very fit man but only survived 10 months after diagnosis.

Recommendation comment:

I think screening should be recommended to help prevent so many deaths from this cancer. Lung cancer is not always linked to smoking and it would save so many lives. It would also give other siblings comfort to know they do not have the illness. After my brother died of lung cancer I worry that I may also have it at some time.

103. xxxx xxxx Member of the Public

Affected Comment:

Yes this condition has affected me and my entire family

Evidence Comment:

Too often lung cancer is Misdiagnosed and attributed to a chest infection or a cold.

If an Xray was done it would pick up lung cancers at earlier stages when treatments and outcomes are so much better.

As the biggest cancer killer in the U.K. it is hard to understand why more is not done

Recommendation comment:

I firmly believe that screening would save many lives by diagnosing at an earlier stage.

We screen for breast and bowel yet, lung cancer being the biggest killer we don't.

Makes little sense

Alternatives comment:

I think early diagnosis is the best way to help people with lung cancer

104. xxxx xxxx Member of the Public

Affected Comment:

My father in law died from lung cancer as a result of not getting an early enough diagnosis of lung cancer from incompetent health professionals

Discussion comment:

No

Recommendation comment:

Yes

105. xxxx xxxx Member of the Public

Affected Comment:

My late husband, Michael, first presented at the GP in August 2009 with a 'strange sensation in the chest'. He was prescribed antihistamine. In January 2010 he was diagnosed with terminal lung cancer. At the point of diagnosis the tumour had spread to his bones, having completely destroyed a rib.

Michael had been a smoker – he was not smoking at the time of his diagnosis. He was 67 years old, fit, slim, a tennis player involved in County Veterans teams. He survived for 14 months from diagnosis – he passed away in May 2011 having endured months of chemotherapy and radiotherapy.

His death was devastating for me, his elderly mother and two brothers and their families. Our lives have not been the same since. He and I lost the retirement we should have had after 50+ years of hard work and contributions to the economy, He was a person who was much loved and who loved life.

Recommendation comment:

I do think screening for lung cancer should be recommended.

If such a programme had existed, Michael's cancer would have been identified much earlier and he would have had a fighting chance of survival. Survival rates for lung cancer have not improved for decades unlike other forms of the disease where screening programmes exist eg breast cancer.

106. xxxx xxxx Member of the Public

Affected Comment:

I lost my husband in March 2020 to stage 4 lung cancer.

Recommendation comment:

Yes screening should definitely be recommended. My husband was stage 4 by the time he was diagnosed and only lived for 9 months from diagnosis. He was given chemotherapy and immunotherapy which initially worked and was shrinking the tumour in his lung. But it was the spread to his liver, lymph nodes, spine and eventually his brain that killed him.

If he had been screened I am certain it would have been detected at a much earlier stage, and treatment could have saved him. Such a waste of a wonderful man, missed beyond measure.

107. xxxx xxxx Member of the Public

Affected Comment:

Yes – friends and family of friends

Evidence Comment:

Not able to say

Discussion comment:

More screening is vital

Recommendation comment:

Yes.

Especially with Covid and how much has been missed

Alternatives comment:

Whilst those at more risk (smokers etc) could have regular checkups, this doesn't pick up those affected who haven't smoked. I can't see how this can be done without screening

Other comments:

Speak to Roy castle lung cancer and other charities

108. xxxx xxxx Member of the Public

Affected Comment:

Yes this condition has affected my friends, one of whom died as a result of it not being detected early enough and another who was screened for an unrelated problem when the cancer was picked up, she was in her 30's, and a non smoker.

Screening saved her life.

Recommendation comment:

Of course screening should be recommended, it can save lives.

Alternatives comment:

Detecting early is the best help for people with this condition.

109. xxxx xxxx Member of the Public

Affected Comment:

I lost my 37 year old husband liam October xxxx 2021

I am so lost without him

Evidence Comment:

People still think it's a smokers disease when my husband never ever smoked

Discussion comment:

Get more awareness out

Recommendation comment:

Definitely as all I am hearing is more people dying of lung cancer

Alternatives comment:

More awareness campaigns and doctors getting patients checked earlier

110. xxxx xxxx Member of the Public

Affected Comment:

LC ravaged my life. I have been in remission for three years but still do not feel well. My family are very concerned with my condition as it limits my daily activities and affects the relationships between all of us...

Evidence Comment:

I can't understand why numerous international studies on lung screening were not considered in the review?!

Discussion comment:

I am outraged that in spite of multitude of international reports on the importance of LC screening the UK government are wasting time and money again on another costly review of something that is so obvious? And think about poor people whose cancers could be missed?!

Recommendation comment:

It should be recommended as it can save time and money in the long run not to mention many lives...

Alternatives comment:

I wonder what alternatives ? It is a well known fact that prevention is better than cure

Other comments:

Improve the whole approach to prevention medicine. At the moment there is no serious medical check programme in the UK. My early lung cancer was found during the comprehensive (included chest x-ray) free medical check abroad as I have dual citizenship.

111. xxxx xxxx Member of the Public

Affected Comment:

Yes I had stage 4 lung cancer on Diagnosis in 2021. I had no symptoms and it was found when I had a CT scan for another condition. If screening had been available it would have been picked up earlier before it spread to my bones

Recommendation comment:

It should be recommended so that people with symptomless lung cancers can be identified before progression has occurred.

112. xxxx xxxx Member of the Public

Affected Comment:

My daughter has lung cancer...diagnosed January 2019.

I wad invited for a lung cancer screening blood test in March 2021 which was negative but there were others who were positive with no symptoms!!

So important this screening takes place!

113. xxxx xxxx Member of the Public

Affected Comment:

I have stage 4 lung cancer.

Evidence Comment:

I was told.by my GP Aug 2020 that he thought i had LC it took.till December I had a treatment plan in place.

Discussion comment:

In America there are a lot of drug trials. And new treatments more readily available.
Here in the UK we are way behind

Recommendation comment:

Yes if more screening was available, then surely ppl would have an earlier diagnosis and treatment would be easier and many lives would be saved.

Alternatives comment:

I feel more advertising and public awareness is needed.

You don't need a pair of lungs to get cancer and you focus on smoking causing cancer. This is not ways the case and ppl.who.havr never smoked will not think to be checked as the focus is on those who.smoke

114. xxxx xxxx Member of the Public

Affected Comment:

I have stage 4 lung cancer diagnosed at an advanced stage. I am a non-smoker

Recommendation comment:

Lung cancer is often detected at a late stage. There should therefore be a screening programme to detect this meaning that individuals have potential to be cured

115. xxxx xxxx Member of the Public

Affected Comment:

I have stage 4 non small cell lung cancer and had no symptoms when I was diagnosed at stage 4. I firmly believe that screening would have been beneficial to my treatment and outcomes.

Recommendation comment:

Screening should be recommended to improve diagnosing early enough to get treatment and have a better outcome

116. xxxx xxxx Member of the Public

Affected Comment:

My son died yesterday of lung cancer (ALK) aged 28 years old.

My son never smoked or took drugs. He was a genetic scientist.

My dad died of lung cancer 7 years ago.

My dad was being treated for a back strain and my son for acid reflux.

They both were not given scans for cancer until it was too late the cancer had already spread.

Doctors need to educated that patients can have cancer at a young age and more scan equipment needs to be readily available to have patients scanned to rule out cancers.

Regular scanning would pick up lung cancer, which we all know can be cured if caught early.

We have to invest in catching illness much earlier this saves lives and saves money on caring for patients in hospital for long periods of time.

Discussion comment:

I would like to see everyone over the age of 50 screened, I have never smoked, due to this fact I would not qualify to be tested that to me is unfair, I am being penalised, everyone should be given the option to be screened

Recommendation comment:

Screening should be available to everyone, no age limit, not everyone will take up the offer of screening. But the information received from this screening will be more valuable and completely outweigh the costs. Once we get a better understanding of lung cancer then research can be targeted in these areas. More and more young people are being diagnosed with cancers, I am fed up hearing, you are unlucky this shouldn't happen to someone so young. My son wasn't the youngest or the only one in his ward, too many young people are dying due to doctors not taking patients' illnesses seriously.

Alternatives comment:

Doctors, GPs need to see patients, stop dismissing patients with 'come back in 8 weeks if things don't improve'. It's the GPs' responsibility to follow up with patients, leaving patients over a number of months waiting for X-rays or scans is no longer acceptable. Stop closing hospitals, we need local hospitals open to provide these scans, so we have the results quickly so treatment can start, this avoids stress and the sooner treatment starts, the results will see an improvement in survival rates.

Other comments:

I feel very strongly that the screening should be available to non-smokers. After my family's experience, how many more non-smokers in my family are going to be effective by lung cancer and not be given the opportunity to have a screening.

117. [REDACTED] Member of the Public

Affected Comment:

Lung cancer is affecting all of us, myself, my family, my friends, my colleagues (I am retired but do voluntary work).

This year I have been diagnosed with incurable quite advanced lung cancer which has also gone to the inner lung lining. This makes it inoperable. I have been told this cancer probably started developing over 3 years ago. It has been hiding inside my left lung without giving clear symptoms until I became breathless in late 2021. I have had a long-term (decades) sinus cough which had got worse a few months before that. I thought all my problem lay within the sinuses. Luckily my GP sent me for a chest X-ray in January, and from there came further tests (CT scan, bronchoscopy etc) and the diagnosis. My situation now is that my best hope is to control the cancer with chemo so I can live well with cancer for some time. They are unable to give me a prognosis until they see how I respond to the chemo, which was only started 6 weeks ago. I am 73 had expected to live another 30 years (my grandmother died at 85 and my mother died at 97) to see my grandchildren reach adulthood. I look after myself, eat properly, exercise regularly, am a healthy weight etc. Cancer was not on my radar, not were lung problems.

Please note I only smoked for 4 years, 10 a day, and stopped around 1978, around 45 years ago. My doctors do not think the cancer is related to that.

If there had been a lung cancer screening program in place this cancer could have been detected much earlier. It might have been contained within the lung itself, would have been operable, and my prognosis would have been excellent.

This is such a scarily common cancer and many lives could be saved and treatments rendered not necessary if it is detected early enough.

Please introduce a screening program.

Recommendation comment:

Yes, absolutely. See my comments in the first box.

Alternatives comment:

This cancer needs to be detected early for lives to be saved.
Please see my story, in the first box.

118. xxxx xxxx Member of the Public

Affected Comment:

I am currently in treatment for lung cancer.

Evidence Comment:

Nurses should be aware that a croaky voice is not always laryngitis. My diagnosis was delayed by about 6 weeks due to this.

Recommendation comment:

Yes it should. Early diagnosis can lead to cure.

Alternatives comment:

Awareness of symptoms
Chest x-rays need to be used earlier.

119. xxxx xxxx Member of the Public

Affected Comment:

Afraid, Lonely, Uncertain for the future, Shocked.

Evidence Comment:

Not sure.

Discussion comment:

Not sure.

Recommendation comment:

It should be recommended especially with covid leaving damaged organs.

Alternatives comment:

Not sure.

120. xxxx xxxx Member of the Public

Affected Comment:

There really aren't enough words to explain what a devastating effect lung cancer has had on my family. Lung cancer is treated like an "own fault" disease & people assume it's a disease that will affect you when you're old. 1977 my grandma was diagnosed and died within weeks.(56yo) Fast forward 2015 -my 54yo husband was diagnosed and dead within 10 weeks. He was the breadwinner. My best friend. A brother, son, husband, papa, colleague, uncle. Many things to many people. He was a funny hard working and kind man.

We have all been deprived of a beautiful human being with the capacity to make a difference to our lives both materially and emotionally.

It seems that nothing much has changed for decades with regards to lung cancer outcomes – but now we have an opportunity to change that. Shouldn't we grasp that? Not only for those who have lung cancer but also for the countless people who are effected not because they have the disease – but because their loved one does.

Screening trials by the Roy Castle charity have shown that cancers can be detected early enough to make a difference to the prognosis. I don't believe they go far enough. My husband and my grandma and my aunty were all under the screening age

Recommendation comment:

Screening absolutely should be implemented – and the trial age (60 I believe) needs to be reduced.

Alternatives comment:

My husband liked smoking. He didn't believe it would kill him in his 50s. He was always "going to give up" tomorrow or next week. I'm not sure that anything would have persuaded him to give up – until he got told he had lung cancer. By that time he was incurable. Had he been able to access screening. Had his cancer been discovered earlier and removed – giving him a cancer free future – he would have been scared out of his skin and sought help to quit from his GP.

121. xxxx xxxx Member of the Public

Affected Comment:

One day I coughed up blood with NO other previous symptoms. I was diagnosed with stage 3 lung cancer a week later. I had Chemoradiation and following this I was lucky enough to have it removed. I was a non smoker..

Recommendation comment:

Definitely, I'd screening had been available my lung cancer could have been picked up at an early stage.

Alternatives comment:

Screening is needed urgently. We have bowel screening and other screenings so why not lung screening, especially as it is the second most common cancer.

122. xxxx xxxx Member of the Public

Affected Comment:

My sister has lung cancer and is currently undergoing treatment. It's a frightening time but hopefully it was caught in good time.

A screening programme must be progress and I would absolutely welcome this change.

Our father died of this disease in 1968 aged 43 when there wasn't readily available treatment and it was seen as a death sentence.

I would welcome anything which helped the early diagnosis of this disease.

Kind regards.

Xxxx xxxx

Evidence Comment:

N/A

Discussion comment:

N/A

Recommendation comment:

I believe screening should most definitely be recommended.

Alternatives comment:

A screening programme would in my opinion be the most beneficial to the nation.

123. **xxxx xxxx** Member of the Public

Affected Comment:

I was diagnosed with EGFR + lung cancer in 2020, aged 48. By the time I was diagnosed, I had a 10cm tumour in my right lung which turned out to be inoperable. My cancer is incurable although it is being treated at the minute with TKI drugs in the form of a daily tablet. I am female and have never smoked. My tumour was visible on a chest x ray, which my GP arranged due to a cough and back pain. If chest x rays or other screening was available on a regular basis, my cancer may have been found earlier and it may have been curable.

Recommendation comment:

Yes I think screening should be recommended. Often, Lung cancer does not present in symptoms until it is too advanced to be treated effectively. It seems that many people with lung cancer are diagnosed by accident when having investigations for other issues.

My tumour was visible on a chest x ray, which my GP arranged due to a cough and back pain. If chest x rays or other screening was available on a regular basis, my cancer may have been found earlier and it may have been curable.

Alternatives comment:

Raise awareness of symptoms, and awareness that lung cancer does not just affect smokers. However, as symptoms often don't present until the cancer is quite advanced I think a screening programme should be investigated and researched as a priority.

124. **xxxx xxxx** Member of the Public

Affected Comment:

The lung screening should be for all. Roy Castle died from lung cancer. Never smoked in his life. Non smokers are at risk too.

Both my parents were smokers and died with lung cancer. Grandfather too.

I grew up surrounded by tobacco smoke and inhaling it. But theres also those in building trades breathing in whatevers around them. Masks dont protect for long.

125. xxxx xxxx Member of the Public

Affected Comment:

My dad died of lung cancer in 2002 aged 58, after the condition was diagnosed too late for him to be cured.

Discussion comment:

Earlier diagnosis through screening could very possibly have saved my dad's life, and allowed him to live longer than his 58 years.

The possibility of short term anxiety and distress caused by the screening process is a small price to pay compared to the alternatives.

Recommendation comment:

I believe it should be recommended.

Cancer Research UK says that the current evidence suggests that breast screening reduces the number of deaths from breast cancer by about 1,300 a year in the UK. This success rate could be repeated by screening long term smokers in the 55+ age group specified.

Alternatives comment:

Smoking cessation programmes are not always successful, particularly for long-term smokers. The addiction is string and difficult to break.

Screening could take place in addition to smoking cessation.

126. xxxx xxxx Member of the Public

Affected Comment:

My father, grandfather and uncle died from this condition.

Evidence Comment:

As smoking decreases we are beginning to see other environmental causes for lung cancer that cannot be controlled by individual decisions. We know that lung cancer has a poor prognosis. Screening for lung cancer will help save lives but it will also develop the narrative around the condition as we learn from early screening.

Discussion comment:

No.

Recommendation comment:

Yes I think screening should be recommended. The stigma around lung cancer has impacted diagnosis and treatment in the past but this is being challenged. Evidence is pointing towards other environmental factors

such as pollution/air quality and I think a screening programme will help develop our understanding of the condition and lead to better treatments.

Alternatives comment:

Stop blaming them for it. The initial assumption if someone has lung cancer is that they smoke – this is being challenged.

Improve air quality/pollution levels.

Engage industry in reducing air pollutants.

Other comments:

No.

127. [REDACTED] Member of the Public

Affected Comment:

We lost our beloved William. A much loved husband, father, father-in-law, grand father and friend to lung disease.

Evidence Comment:

Williams lung cancer was spotted following an x-ray on his leg! After experiencing difficulties walking.

If lung screening has been available it would have been detected earlier than stage 4!

Discussion comment:

Regular screen is vital to maintain the general public's health.

Recommendation comment:

One million percent think it should.

Alternatives comment:

More emotional and financial support.

Other comments:

No

128. [REDACTED] Member of the Public

Affected Comment:

Screening should be implemented as soon as possible.

129. [REDACTED] Member of the Public

Affected Comment:

Due to covid my dad was fobbed off for over a year before his lung cancer was discovered at stage 4 and given 18m to live. He was fobbed off despite having a persistent cough which was worsening and several chest infections, screening would have surely diagnosed him at a much earlier stage or even after a shorter

time than a year. It has affected our whole family and we are gutted that a usually healthy man will have his life cut short and won't see his grandchildren grow up esp hard as my mother also died of blood cancer at age 62.

Recommendation comment:

Should be recommended as this cancer has the worst prognosis and is common. Surely screening would catch it at an early stage and give people a chance of loving longer.

Alternatives comment:

Awareness of symptoms to public and gps and medical people do that diagnosis can be made earlier, at the very least.

130. [REDACTED] Member of the Public

Affected Comment:

My father died of lung cancer. Early signs of the disease were missed by doctors and so the cancer had metastasised by the time he was diagnosed. My father had never smoked.

Recommendation comment:

Screening may enable lung cancer to be detected in certain individuals at a much earlier stage thereby allowing more effective, potentially curative, treatment

Alternatives comment:

Given that lung cancer is such a common type of cancer and currently has a very poor over all prognosis (largely due to the late stage at which the disease is diagnosed in many individuals) the level of funding for research into causes of the disease and possible treatments, falls far short especially in comparison to other types of cancer- this disparity needs to be addressed.

In addition, further education as to the potential clinical signs of lung cancer needs to be provided to all healthcare professionals as sadly warning signs of lung cancer are often missed by practitioners especially if there is no history of smoking in the patient.

131. [REDACTED] Member of the Public

Affected Comment:

My mum was young at heart all her life. Rarely sick. She "collapsed" and within hours was diagnosed with lung cancer and brain metastases at age 65 and died at 67. A beautiful life cut short. Screening may have saved her. We'll never know.

132. [REDACTED] Member of the Public

Affected Comment:

Yes my husband died of lung cancer within 4 months from initial diagnosis. He was a non-smoker

Recommendation comment:

Yes I do think screening should be recommended. Other than a cough, my non-smoking, otherwise healthy husband had no other symptoms to suggest it was cancer.

When cancer was confirmed he was already at stage 4.

Maybe earlier screening could have given him more options and possibly have prolonged his life.

Alternatives comment:

There is no emotional, or practical support groups for lung cancer patients within the NHS. Help comes from outside organisations such as Macmillan

133. xxxx xxxx Member of the Public

Affected Comment:

Yes, my aunt died of lung cancer, had this been diagnosed sooner she would still be alive today.

Recommendation comment:

Yes, screen should be recommended.

134. xxxx xxxx Member of the Public

Affected Comment:

My mother was only 62 when she was diagnosed with stage 4, EFGR lung cancer. This was exactly ten years after my grandfather (her father) had been diagnosed and died from lung cancer.

My mother's tumour initially responded well to Afatinib. However, the drugs stopped working after about 14 months, this was during the initial lockdown, and despite gaining funding to try a third generation drug the tumour continued to grow. My mother also developed blood clots and became so weak she couldn't continue with her chemo and subsequently died.

She had never smoked and her diagnosis and death were harrowing not just for her but for all of her family. She managed to survive for 3.5 years.

Evidence Comment:

I think that since 2007 the prevalence of lung cancer in women whom have not smoked is too high now for it to be ignored.

Results from America are showing that screening is catching cases of lung cancer in its early stages which can then be treated.

The death sentence that most people, now seemingly mostly women, receive when given a lung cancer diagnosis in this country needs to be halted.

It is also wrong to keep looking at results from 2007. Over ten years ago have passed and the research on lung cancer has provided new treatments which combined with a screening programme could massively turn this horrendous disease into something that people could live with.

Discussion comment:

It's appalling that guidelines agreed upon in 2007 are still being used as evidence in 2022.

Recommendation comment:

I think that screening should be used as a vital tool in the combating of this disease. If lung cancer can be caught in its very early stages it is treatable. Women should not be dying twenty years too early because their lung cancer is diagnosed too late for treatment.

Alternatives comment:

Lung Cancer needs to be addressed as breast cancer and ovarian cancer are. It is no longer just a disease of smokers. Anyone who has lungs may develop lung cancer and due to the closeness of the lungs to the heart, tumours which develop near this organ are often inoperable.

The whole concept of lung cancer needs to be addressed. People need to be educated and made aware that it is no longer a rare cancer. It is a harrowing illness and the sooner cases are caught in the early stages, the better.

135. xxxx xxxx Member of the Public

Affected Comment:

I was found to have lung cancer stage 1 on a routine x-ray at age 55 I was very fortunate and had right middle lobectomy and have been clear for 6 yrs. I was not a smoker and had no outward symptoms I think screening could play a very important role in early detection and save many lives I have a husband and 3 sons and 3 grandchildren. Early detection is crucial. Surely early detection would put way costs of treatments for later stage detection and the heartache of only finding out at a later stage. This condition and it's mortality rate must be put higher up the priority along side other common cancers which have far better screening programmes and advertising

Evidence Comment:

No comment

Discussion comment:

No comment

Recommendation comment:

I think screening should be considered with the same importance as breast cancer, bowel cancer,cervical and prostate cancer. People need to be made aware and I can only emphasise that incidental findings save lives

Alternatives comment:

I think the government should follow up lung cancer patients for longer than 5 yrs. As lung cancer does not show symptoms until later stages how would I know if it is slowly coming back if I'm not checked after 5 yrs surely it is more cost effective to keep following up with yearly check ups to check for recurring cancer. psychologically it is very scary to just be told 5 yrs are up with no follow up support.

Other comments:

I think the television and media campaigns are brilliant at highlighting this condition recently and I hope through this that more awareness is made available. I think it should also be emphasised that people can get lung cancer even though they don't smoke or have never smoked.

136. xxxx xxxx Member of the Public

Affected Comment:

My mum was diagnosed with stage 3C lung cancer after 2.5 years of repeated doctors visits of a worsening cough.

Recommendation comment:

Screening should be recommended. After 2.5 years of misdiagnosis by GPs my mum was diagnosed with stage 3c lung cancer that she is now too weak from to have treatment. Screening could have picked up an earlier diagnosis and saved her from that awful fate she now has.

Alternatives comment:

Practitioners to actually listen to patients worries and do the reasonable examinations and tests if symptoms don't improve after a couple of weeks/months

Other comments:

To give more funding to cancer and guidance to practitioners in diagnosing earlier

137. **xxxx xxxx Member of the Public**

Affected Comment:

With a long family history of lung cancer I feel this screening will make diagnosing lung cancer a lot quicker process. Instead of waiting till symptoms are bad and with the long doctor/hospital waiting list this screening will speed up the process hopefully resulting in less deaths by diagnosing earlier

Discussion comment:

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Recommendation comment:

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Alternatives comment:

Right now I don't feel enough research is being put into lung conditions to help find treatment. I would like to know what alternatives there is that will be as effective & quick as screening

138. **xxxx xxxx Member of the Public**

Affected Comment:

My mum had ALK positive lung cancer -she never smoked, was healthy and was diagnosed in her 50s (outside the typical age bracket). Because she did not fit into any of the risk factors, her GP did not consider her to be at risk of lung cancer and was instead given multiple rounds of antibiotics. By the time she was officially diagnosed, the lung cancer had metastasized and she was at stage 4 and therefore incurable. This has been particularly devastating for our family because my mum did all of the right things in seeking medical help but because she did not fit the typical pattern, she fell through the cracks and was not given the opportunity to try to cure the cancer. I therefore would urge the UK NSC to extend the remit of the lung cancer screening to those individuals, like my mum, who do not fit the typical profile of a lung cancer patient.

Evidence Comment:

I don't believe the impact lung cancer has on non smokers has been considered. There is a vacuum which must be filled as non smokers are constantly excluded and this is costing lives.

A low dose CT scan should be available to patients / cases where it would be considered prudent or appropriate for the patient given the particular fact pattern of their case / family history. For example, individuals who have a persistent cough (which is the only symptom my mum had) should be given an opportunity to have a low dose CT scan. It is well known that x rays alone do not reliably capture lung cancer when it is at a stage where it could be cured. In order to be able to catch lung cancer earlier, a low dose CT scan should be rolled out to more individuals, irrespective of their smoking history / age, in order to save lives.

Discussion comment:

I agree and fully support the overall scheme proposed but I would encourage the UK National Screening Committee to extend lung cancer screening not only to those individuals who have smoked but to those who have never smoked and do not fit the typical profile of what a lung cancer patient looks like. More needs to be done for non smokers who get lung cancer.

Recommendation comment:

Yes, it should be recommended. Lung cancer is the third most common cancer in the UK and it does not get the funding or assistance it desperately needs to tackle this disease.

Alternatives comment:

Whilst the screening program is a significant improvement and the right way to improve patient outcomes, it is also important that the toolbox to fighting lung cancer is also strengthened and a holistic approach is taken. I have outlined below a few suggestions which could in conjunction help deal with the gap:

1) GPs need to be alert that anybody can get lung cancer, irrespective of whether you have smoked or not. If you have lungs, you are at risk of lung cancer and more needs to be done within primary care to identify cases earlier instead of prescribing antibiotics on the assumption that it must be a chest infection if you are relatively young and a non smoker.

2) Furthermore the number of people diagnosed each year with non smoking lung cancer is on the rise and further research by the government is needed to understand why this is the case. Given the stigma of smoking (i.e. the perception is that it is a self inflicted disease because one chooses to smoke), research for this type of cancer is low. The government must provide funding and raise awareness for lung cancer to ensure adequate resources are given to research in this area.

3) In addition, once a patient has been diagnosed with lung cancer, the treatment options on the NHS needs to be broadened. The NICE guidelines only allow a patient to exhaust two TKIs whilst other countries around the world have 5 TKIs at their disposal. The NICE guidelines are too formulaic, rigid and not fit for purpose at a time when the cancer world is striving forwards and delivering targeted treatment. This is the future of cancer care and the NICE guidelines deprives patients of treatment options which could extend their life and allow them more time with their family and friends.

Other comments:

A solution needs to be founded and adopted soon to help save lives. There is currently a gap to diagnosing and treating lung cancer patients and it is welcomed that the UK National Screening Committee is now considering closing the gap by introducing a screening programme which could catch lung cancer early enough to cure the patient.

Given that it is still unknown why non smokers get lung cancer, and why the rearrangement of the ALK gene (and other genetic mutations such as BRAF, ROS, EGFR happens), it is vital that any scheme that is implemented remains flexible, especially in relation to the eligibility criteria. It is essential that non smokers are also able to participate in the screening. Otherwise, the risk is that you miss a significant part of the

population affected by this horrendous illness – they become lost and are failed by the system, like my mum was. The screening program needs to be ambitious in order to cover as many situations as possible.

Overall, the National Screening Committee needs to put this high on its agenda and adopt this proposal urgently, with the suggested amendments herein, and move swiftly with its implementation.

139. xxxx xxxx Member of the Public

Affected Comment:

My father passed away aged 58, 6 weeks after his diagnosis of Lung Cancer. His mum (my Grandma) also died of the disease in her 70s. My dad was a non-smoker. He he had been diagnosed earlier, as it was already in the family, maybe we would've had him longer. I am worried that I will also get it. Once symptoms exist, its normally too late to save the person.

Recommendation comment:

Absolutely should be recommended! My father (non-smoker) died 6 weeks after diagnosis aged 58, once you get symptoms, it's too late! We are screened for breast, cervical, prostate...why not lungs?! You could save hundreds of lives.

140. xxxx xxxx Member of the Public

Affected Comment:

This is so important to get screening in place for lung cancer x terrible disease and so important to detect early. It save money and suffering, hospital places and doctors time to get early. Its no brainer. I have relative who died from it being diagnosed way to late and was awful for all concerned x prevention better than cure !!!

Recommendation comment:

Theres always risk of missing things or false positives or negatives but overall screening could help with early diagnoses and offer treatment to those who other wise would be missed until lung cancer had set it

141. xxxx xxxx Member of the Public

Affected Comment:

I lost my dad at 59 years old to lung cancer in 2020. My dad had ALK+ lung cancer and received targeted therapy for 2 years before he passed. This has devastated our family as had there been a screening programme available it might have been caught before it got to stage 4 and he could have still been here now. My friends mum was also diagnosed with stage 4 lung cancer in December 2021 following a local screening programme, she had no symptoms and so she was very lucky to have had the opportunity of this local screening programme.

Recommendation comment:

I 100 percent believe screening should be recommended. There are many genetic mutations of lung cancer affecting people who've no idea about these specific types. Sadly because the majority are non smokers it's brushed off as asthma, viral etc and is often caught at stage 4 which is too late. If screening was in place this could at least give people a little longer with their families and if caught early enough even cure them fully. 96 people die each day from lung cancer and this could be prevented if screening was introduced.

Alternatives comment:

Lots more information regarding lung cancer and the genetic mutations that can affect non smokers. Lung cancer is always seen as an old peoples smokers diseased and this simply isn't the case anymore. People need to know the symptoms and GPs need to also be educated and consider referring people earlier and not fobbing them off for 18mths which then means cancer has spread and unable to be treated.

142. xxxx xxxx Member of the Public

Affected Comment:

Yes, my dad died very suddenly of mastamic lung cancer. I welcome screening 100%

Recommendation comment:

Screening should be recommended, as it's a real killer, and people don't know they've got it until sometimes too late, it's also still thought that it's a smokers disease and people judge on that fact, thinking its there own fault.

143. xxxx xxxx Member of the Public

Affected Comment:

Yes, my sister died of lung cancer 3 years ago aged just 47 years old. If there was a national screening program in place, maybe the cancer would have been caught earlier for her? She was told it was terminal & she was taken from us only 5 short months later.

These poor people who are one day living healthy, happy lives thinking they have years ahead of them, are then given the shock that they have only months to live.

It's crazy, if we have the technology to catch lung cancer before it's too late, why don't we use it. So many families are torn apart by these tragic stories. I know of 2 other families who have lost family members to lung cancer. Surely, if its the 2nd most common cancer, there should be more schemes in place to prevent or catch it before its too late.

Recommendation comment:

It should be recommended! To help catch lung cancer before it's too late.

144. xxxx xxxx Member of the Public

Recommendation comment:

I think it should be considered

145. xxxx xxxx Member of the Public

Affected Comment:

My mum and dad has had Lung cancer my dad 18years ago and he survived an op and had chemotherapy he had symptoms, but sadly for my mum it was very different she didnt have symptoms until.the very end it had reached stage 4 and no option for treatment she died only 3 weeks after been told she had cancer this was only 1 month ago as u can imagine my life has been shattered my mum also was a non smoker i think Lung cancer screening could of saved her life

Recommendation comment:

Defo recommended as with lung cancer symptoms can happen too late

146. xxxx xxxx Member of the Public

Affected Comment:

I lost my husband of 43 years to this horrible disease two and a half years ago. I will never forget whst he went through and how he suffered. I miss him terribly and would do anything to get him back. The screening could have saved his life, he was 68 years old when he died.

Recommendation comment:

Screening should definately be recomendef

Alternatives comment:

Screening could save thousands of lives. People like my husband would not hseve to suffer.

147. xxxx xxxx Member of the Public

Affected Comment:

Yes. Both parents of a good friend have suffered from lung cancer.

Recommendation comment:

It should be recommended as it would detect the cancer earlier, potentially reducing the cost for the NHS in long term treatment and more invasive procedures

148. xxxx xxxx Member of the Public

Affected Comment:

My friends mum, screening shpukd be done

149. xxxx xxxx Member of the Public

Affected Comment:

My grandmother died of lung cancer and my best friends mother died of it too

Recommendation comment:

I do think screening should be recommended – lung cancer is a cancer that is often diagnosed at a later stage, when health outcomes for that individual are then poorer as the cancer is at a later stage when it is discovered.

Alternatives comment:

More public health info about the symptoms of lung cancer – lung health checks with yr gp, with discussions about lifestyle and symptoms etc

150. xxxx xxxx Member of the Public

Affected Comment:

Yes, a friend has passed away with lung cancer. She was only 69.

Recommendation comment:

Yes screening should be allowed, early detection, more accurate diagnosis.

151. xxxx xxxx Member of the Public

Affected Comment:

I have recently lost an aunt to lung cancer. She was diagnosed too late for treatment. Her husband survived lung cancer after surgery to remove 1 lung plus chemotherapy at Broadgreen hospital, Liverpool.

Recommendation comment:

Screening for families with high/unusual rates of lung cancer should be screened

152. xxxx xxxx Member of the Public

Affected Comment:

If this Cancer is the 2nd most common killer and kills around 38 000.

Why is there No screening for the disease ?

Discussion comment:

My best friends Mother and Father were both diagnosed with lung cancer Her Mother was diagnosed but unfortunately died 3 weeks later without ever having a chance of treatment

Her father was diagnosed and luckily he did get treatment and is making a good recovery. This was absolutely heartbreaking for the family to lose their Mother without her even being given the chance to fight it.

If it had been screened for she too would probably still be here today.

Recommendation comment:

Should be screened for...

Why ? Because every human beings life is precious not only to themselves but to their family.

153. xxxx xxxx Member of the Public

Affected Comment:

Family friends mum

Evidence Comment:

No

Discussion comment:

Really to diagnose and treatment to be started early, early screening

Recommendation comment:

Screening in place to detect early disease and has been so fantastic in early detection of other cancers eg cervical, bowel

Alternatives comment:

More education and awareness

154. xxxx xxxx Member of the Public

Affected Comment:

I lost my dad to lung cancer and if there would have been screening available, he would still be with us today

Discussion comment:

Recommend everyone over the age of 60 gets screening.

Recommendation comment:

Yes to detect lung cancer sooner

Alternatives comment:

Personally, screening is the best way to spot this illness sooner

155. xxxx xxxx Member of the Public

Affected Comment:

My Dad was diagnosed with stage 4 inoperable adenocarcinoma in 2011 at the age of 66. This was only found after repeated attendances at his GP practice about a persistent cough and being given antibiotics. Thankfully, the last GP he saw sent him for an x-ray and cancer was detected. He had retired a day earlier and in preparation, had undergone a full medical several months before so he could enjoy his retirement without worry. As lung cancer isn't screened, his large tumour wasn't found. After diagnosis, he underwent months of debilitating chemotherapy and radiotherapy. After the tumour had reduced enough, an operation took place to remove part of his lung. An additional spot was seen near his ribs but the doctors wanted to concentrate on the most life-threatening tumour first. A couple of years later, the cancer returned at that spot and required another operation where parts of his ribcage were removed and more debilitating treatment was undertaken. Whilst he has survived his ordeal, he has been left in poor health and his life is limited because of his now poor lung capacity. He still struggles with activity and has ongoing neuropathy. Had routine screening taken place during his lifetime, the tumour may have been found earlier and treatment would have been less invasive.

Recommendation comment:

Screening should be recommended for the reasons already stated. I also believe it would cost the NHS less. Earlier detection means less invasive and shorter treatment with better life expectancy and quality of life.

156. xxxx xxxx Member of the Public

Affected Comment:

It affected me 4 years ago and I still suffer the after effects

Recommendation comment:

Most definitely should be. Many do not know they have lung cancer until it is too late. If you are a non smoker then this condition is often not even considered. A simple xray would pick up many issues that could be addressed earlier. Resources should be targeted to prevent or detect earlier. Lung cancer can hit anyone and just to target smokers but saying stop smoking ignores these who never smoked but develop Lung cancer.

Alternatives comment:

Lung cancer is silent for so long. Capturing it early gives you a chance of living a full life. Screening is by far the best option. However you need to move away from the smoking causes cancer message. People think if they don't smoke they can't have cancer so ignore the warning signs. Tell people anyone can get lung cancer. Tell them what to look out for. Re train doctors so they are not dismissive of symptoms because they are facing a non smoker. Invest in education about the long term effects of Cancer including the PTSD that can occur


Other comments:

Test and educate. Address the stigma of lung cancer. The idea that it's your fault you got cancer. Stop blaming the victim-you wouldn't do it to a breast cancer patient. I have had numerous people ask me if I am a smoker when they heard about my lung cancer inc doctors. No I didn't smoke. People should understand you only need lungs to get long cancer. Smoking cessation promotion is good but you need to focus on lung cancer, signs and symptoms, tag line you only lungs to get lung cancer. Also five year screening X-ray could pick up lots of issues. Plus post treatment much more pulmonary rehab classes, mental health support, help with breathlessness, chronic fatigue. Invest in understanding how and why people get lung cancer instead of just focusing on smokers. More younger people are now getting Lung Ca and their lives are being destroyed- it's one of the most common cancers but this notion that victims are to blame for this cancer mean there is far less investment in research. I AM A NON SMOKER. I HAVE HAD LUNG CANCER I HAVE LOST PART OF A LUNG. MY LIFE HAS BEEN TURNED UPSIDE DOWN. I DONT WANT OTHERS TO EXPERIENCE WHAT I HAVE. Test and educate. Research reasons and treatments. The Gov anti smoking program has sent out a mixed signal. People with classic symptoms don't seek early help because they don't smoke so it can't be lung cancer. So again screen regularly, educate, and for the love of god remember YOU ONLY NEED LUNGS TO GET LUNG CANCER.

157. xxxx xxxx Member of the Public

Affected Comment:

It is vital that this screening goes on for everyone not just those at risk. It could save many lives and could be the difference between life and death.

My son died of lung cancer in 2017 aged 29 his GP wasn't even looking for this as he was so young so it took six months before he was actually diagnosed. Much too late. 4 months later he was gone. ??? Where is the sense in that????? 

Recommendation comment:

Screening is vital to prevent death, early diagnosis is vital to saving or prolonging life.

Alternatives comment:

Screening is the best option. Using other methods lung cancer can still be missed as in my son's case.

Other comments:

GP's need to be more aware.

158. xxxx xxxx Member of the Public

Affected Comment:

My husband and twin sister both had lung cancer I live in fear for my turn. Horrific to be part of the dieing process Time to scan and catch this best early

Recommendation comment:

100% I think it should be screened

159. xxxx xxxx Member of the Public

Affected Comment:

My mother's friend

Recommendation comment:

Should

160. xxxx xxxx Member of the Public

Affected Comment:

Just lost 2 brothers within 6 months to lung cancer

Recommendation comment:

I beleive screening could detect early signs, there resulting in earlier treatment.

161. xxxx xxxx Member of the Public

Affected Comment:

Yes it has affected the family

Evidence Comment:

Screening should be made compulsory

Recommendation comment:

Made compulsory

162. xxxx xxxx Member of the Public

Affected Comment:

I discovered my own lung cancer when I brought blood up in my sputum. Within a few short weeks I had scans, including a PET scan and a referral to xxxx xxxx hospital. My wonderful surgeon Doctor xxxx xxxx informed me I had a 6.5cm tumour in my left lung. Unless I had the tumour and possibly the lung removed I would potentially die within 12 months. I elected for surgery and donated the tumour to one group for research and the lung to another. I also signed up to the Geno project to donate blood every 6 months for research. Early screening will more people, more chance to live longer and hopefully lead to more research and better outcomes. As a result of mine being found I am now 4 years post op. Thank you

Recommendation comment:

Anything that finds disease earlier will save lives.

Alternatives comment:

Mandatory x-rays or scans every so many years.

163. xxxx xxxx Member of the Public

Affected Comment:

My Mum was diagnosed with stage 4 lung cancer 10 years ago. Once diagnosed she lived for 18 further months. This is a cruel and unforgiving disease and I truly believe that screening will help detect early stages of lung cancer which will give so many more people hope and ultimately a better chance of survival.

Evidence Comment:

The gender data split wasn't mentioned? Do findings conclude no statistical significance for both men and women? Secondly, those that were diagnosed in the early stages through screening – did they have better survival rates vs those diagnosed in later stages?

Discussion comment:

As the report confirms the theoretical basis of LDCT, in that more lung cancers are diagnosed in the earlier stages and fewer in the later stages, surely this is a great result for demonstrating the positive impact that this could have on so many people's lives?! And firstly you cannot put a price on someone's life. Secondly if you're going to – surely it is more cost effective to diagnose/treat someone early to give them a better chance of surviving and going on to live a life where from example they are able to return to work and contribute to the economy. Rather than diagnosing late and

paying for treatment that had a much higher chance of being ineffective in the long run.

Recommendation comment:

I think it should be recommended to enable early detection of lung cancer.

Alternatives comment:

Mainly – trust patients when they are reporting symptoms to the GP and don't assume it is a cold/chest infection/pneumonia. Train our doctors and GP's to act with compassion and air on the side of caution if a patient knows they are not well in themselves.

164. xxxx xxxx Member of the Public

Affected Comment:

My wife died of lung cancer at the age of 58 and 22 years after she ceased smoking. She was very fit and healthy before falling ill to cancer. Her early symptoms were initially misdiagnosed causing a delay of around 12 weeks, before experiencing a transient ischaemic event and receiving a diagnosis of stage 4 lung cancer.

Recommendation comment:

YES! Technology such as circulating tumor DNA sequencing has the potential to transform early detection. The costs of this are minuscule (and would decrease if used at high volume) compared to the huge cost of treatment and of course the cost in suffering of the brutal illness, treatments and loss of cherished lives.

Alternatives comment:

Educate GPs not to brush off the early symptoms of lung cancer as happened in my wife's case even when I prompted them about the possibility. When symptoms could point to either a minor or deadly diagnosis then the default should be to address the most serious possibility, not assume the most minor explanation.

Other comments:

Society and the medical profession should stop treating lung cancer patients with disdain. Many highly motivated, educated, productive generous and wonderful human beings were foolish in their youth and became hooked on smoking.

165. xxxx xxxx Member of the Public

Affected Comment:

I am 59 and I am waiting for results of a lung biopsy, after a routine X-ray and CT scan showed a 5.3cm mass and multiple metastasis on both lungs. Other than a minor cough I had no symptoms. It's likely that my cancer is incurable. I am getting married in less than 2 weeks and had a lifetime of plans to look forward to. A viable screening programme may have given me an earlier and more treatable diagnosis. My family, friends and I are all devastated.

166. xxxx xxxx Member of the Public

Affected Comment:

Cancer in many body sites that

Evidence Comment:

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Discussion comment:

167. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with stage 4 lung cancer in 2018. With screening my life would be very different.

Recommendation comment:

It should be. Lung cancer is the biggest cancer killer in the world and the most underfunded.

Alternatives comment:

Education for the medical community who miss many signs.

168. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with Stage IV NSCLC in December last year, while on maternity leave (aged 40). I had no obvious lung symptoms... just shoulder pain, which was put down to musculoskeletal issues. I have never smoked.

Evidence Comment:

The data used in the mortality curves seem out of date (2016 and 2018). They don't take into account treatments that have been developed in the last few years, and are prolonging survival.

Discussion comment:

Age and gender should be taken into account with screening. In particular, there is a significant increase in the number of young, female never smokers who are presenting with LC now. Currently, there is no screening opportunity for us. There should be. Risk factors need to be updated to reflect this shift in the demographics.

Recommendation comment:

Recommended. LC is usually detected at later stages. The earlier it is detected, the easier it is to treat. New developments in treatment also mean that survival rates are increasing (beyond that seem in the stats presented in the report).

Alternatives comment:

Easier/faster access to drugs, that have been shown to be effective in RCTs elsewhere (and are used in standard treatment in other countries). Needing to show progression on first line treatment (usually chemo or early TKIs) before these drugs are offered is problematic, as it may mean patients are too unwell for these drugs by the time they get to use them.

Molecular profiling of tumours should be offered as standard, to better direct treatment.

Other comments:

See above.

Also-more transparency around treatment options and how to access them.

169. xxxx xxxx Member of the Public

Affected Comment:

This condition has affected my closest friend at the age of only 37. After researching and hearing more and more how certain mutations of lung cancer are affecting all ages, I believe it is vital to screen for lung cancer. My friend is 37 with terminal cancer, that was misdiagnosed on several occasions due to her age. I believe if there were a national screening for this condition my friend may have been diagnosed at an earlier date meaning her diagnosis may have been different to terminal.

Recommendation comment:

I 100% believe screening should be recommended. This condition has affected my closest friend at the age of only 37. After researching and hearing more and more how certain mutations of lung cancer are affecting all ages, I believe it is vital to screen for lung cancer. My friend is 37 with terminal cancer, that was misdiagnosed on several occasions due to her age. I believe if there were a national screening for this condition my friend may have been diagnosed at an earlier date meaning her diagnosis may have been different to terminal.

Alternatives comment:

By taking symptoms seriously, even if you are younger and don't "typically" fall in to age group that lung cancer is more related to.

170. xxxx xxxx Member of the Public

Affected Comment:

My best friends mum, who was only 67 years old, went to her GP feeling run down with mouth ulcers. She wasn't sent for any type of screening. She went back 3 to 4 times a week telling the doctors she knew she was ill and needed help.

6 months on, finally someone listened. She had a scan, diagnosed with Stage 4 incurable lung cancer.

Within 2 weeks she was dead. She had no other symptoms apart from ulcers and being run down.

The family were told it was an aggressive type of lung cancer but if she had been screened when she first went, it would have saved her life, sparing the agony for her children and young grandchildren who now grow up without their doting Nan. They are broken, most are in counselling – one grandchild is currently struggling through his GCSE exams.

This heart break could have easily been prevented, she could have received treatment to prolong her life, enable her to watch her family grow up. Screening is essential if we are to save money on the NHS as treatment will be given quicker and it may not be so prolonged. It will also prevent families being destroyed so quickly and their faith in our amazing health system has been shattered.

My good friend was also diagnosed with lung cancer – age 42. She was screened, treated with chemo, radiotherapy and drugs. This prolonged her life for 2 years – in that time she lived life to the full, giving her precious time and experiences with her loved ones. She died last Monday, but died knowing she had left the world a better place after fund raising and spending time really getting to know the ones she loved, giving them precious memories. Everyone deserves this.

Discussion comment:

Screening must be routine and done regularly for the over 50's. It should be as commonplace as breast cancer screening and "The big C" must not be a taboo any more.

Recommendation comment:

It should be – it would prevent so many premature deaths and give people time with their families.

Alternatives comment:

How can lung cancer be diagnosed without screening? If we could prevent cancer we would through lifestyle changes etc but that doesn't stop it! If there is a way, tell us – don't lecture – advise! Most of the population are intelligent people who have the freedom to choose. Let them choose.

I had a health check including bloods at 40 – make it compulsory for all every 5 years – blood test is cheaper than scan. Women already have breast and cervical screens and this has saved thousands of lives, just make it all compulsory for men and women.

Other comments:

Screening for everything would be fabulous wouldn't it? As part of a health screen at 40, 50, 60 and 70? It would be an extra burden but ultimately save time and money further on on more invasive treatments and therapies.

171. xxxx xxxx Member of the Public

Affected Comment:

My husband was diagnosed with NCS in April 2019 when i was 6 months pregnant. This was found on a chest X-ray ahead of another routine procedure. Although he has previously smoked and quit the consultant felt his type of cancer was not due to smoking.

His consultant strongly felt that he was the type of person who would have benefited from a screening programme.

He had a lobectomy and so far surveillance has shown no known recurrence.

The evidence I have read in BMJ and on Pubmed all indicate that early diagnosis is key. We were lucky that early diagnosis was picked up by happenstance however changing screening advice could take this chance away for patients.

Evidence Comment:

I found it very difficult to view the documents the link failed multiple times.

Recommendation comment:

Yes I do.

Roy castle foundation suggests 77% of diagnosis are caught early with screening in place.

To find more lung cancer when there can be treatment offered with curative intent.

To avoid a postcode lottery of management.

Alternatives comment:

Better promotions of symptoms.

Decrease the feeling that only smokers get lung cancer.

Education of primary care/ GPs- we had to fight for review of X-ray which a receptionist told us was normal

Raise profile of lung cancer survivors

Increased research in to long term survivorship

172. xxxx xxxx Member of the Public

Affected Comment:

I received he devastating news in November that my female friend of 36 was diagnosed with terminal lung cancer. She has non small cell lung cancer in both lungs and the cancer spread to her hips and pelvis.

She was dismissed by her GP on several occasions for a crackle in her throat, shoulder pain and a lump in her neck. All symptoms of lung cancer and no one thought to piece them together.

It was only because my friend was so concerned about the lump in her neck she requested a face to face appointment and they performed a biopsy.

This could have been prevented if her GP referred her sooner or a screening was done.

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

It should be included for the simple matter that prevention is better than cure.

Cervical screening/mammograms are all screenings that are recommended the public have based on specific criteria, age for example.

The report says lung cancer is becoming increasingly common in younger people, and more so women this is enough evidence in itself.

Other comments:

I don't know how GPs work and what systems are in place but now that you barely get the chance to see your registered GP or even get to see one face to face these days, they should perform routine reviews of patients to connect the dots and see if there is a connection in the past 5 doctors visits.

173. xxxx xxxx Member of the Public

Affected Comment:

I was lucky to have my lung cancer diagnosed when it was. My cancer is inoperable so incurable but is stage 3c so I have been able to have treatment that has slowed the cancer down, another few weeks and it would have been stage 4 and I may not have been here now. Lung cancer is one of the biggest killers and has a pitifully low 5 year survival rate, it's also viewed as almost self inflicted due to its links with smoking whilst cancers that have alcohol as a causal factor are not regarded in the same way.

I feel that the stigma attached to lung cancer has resulted in a lack of education as well as a lack of funding for this killer. Due to the lack of education and social awareness of the symptoms of lung cancer as well as the almost total denial that none smokers die of lung cancer the public ignorance of this terrible disease remains disturbingly high.

A screening program coupled with a national education program will result in earlier diagnosis and in a higher survival rate.

174. xxxx xxxx Member of the Public

Affected Comment:

My father passed away from lung cancer in 2020 just 8 weeks after being officially diagnosed. He had been previously admitted to hospital in August 2019 due to his diabetes and was told he had a chest infection, given antibiotics and sent away with no follow up. He had no signs of a chest infection other than his blood tests being abnormal. December 2019 is when he developed a cough and feeling unwell, 4 weeks later he saw a GP and a week later got an x-ray appointment. But by this point it was already advanced to stage 4.

My father got the official results of it being cancer on xxxx January 2020 and died on xxxx march 2020 with supposedly a non-aggressive lung cancer.

Discussion comment:

I don't fully understand how a breath test can determine lung cancer but as with my dad a simple blood test showed up that something wasn't right, even though we were told nothing would have shown up on an x ray at that point the blood tests said otherwise..it was just never followed up with anything.

Recommendation comment:

Screening should 100% be recommended. It is the most deadly cancer world wide and the second most deadly in the UK. That is enough to say we have to do more. With lung cancer and like with my dad, the symptoms don't emerge until it is too late and too advanced meaning there is little or no treatment that can prevent death or a short life. My dad actually started to develop lung cancer in August 2019 and 6 months later it was too late and he never even got chance to have one treatment to try and save him. If screening would have been done after his abnormal blood tests had come back then there might have been a chance it could have been caught early enough to try and do something about. Screening needs to be implemented. With most other cancers you can get early warning signs, you feel a lump, no notice changes in your body. With lung cancer you don't until it's too late and too advanced. screening could significantly help or at least give longer survival rates by catching the cancer early.

Alternatives comment:

The earlier it is caught the better....not making people wait 3 weeks with a cough before a gp agrees to an x ray....3 weeks could be detrimental in time when it comes to having tests etc done. They say that if it is suspected cancer then they will be referred to the hospital within 2 weeks, I believe that if it is suspected cancer then all tests needed to give a final diagnosis should be completed within the 2 weeks ready to start treatment asap. Cancer takes no prisoners and unfortunately we are not treating people early enough to help with survival rates. GPs aren't taking concerns seriously enough....people know their own bodies but GPs seem to think antibiotics is always the first thing to try before even considering that it could be cancer if you don't fit in a certain age range or medical history. The first thing that should always be ruled out is cancer and then look at other options because 1 in 2 people are diagnosed with cancer, the odds are unbelievably sad and everyone needs to be doing more.

175. xxxx xxxx Member of the Public

Affected Comment:

Yes, my husband had lung cancer.he died from a ruptured aorta at home one night which was the most horrendous thing iv every witnessed and will never forget nor will our 11year old son!!!!!!this was only 9 months after diagnosis,he only had the diagnosis because he started coughing up blood,he had COPD so was just told oh it's the COPD!!!!!! Just maybe if he'd been screened ?????!!!!

176. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with incurable lung cancer in Feb. Never smoked I'm 44 years old. Please let's help future people catch this early enough so it's not incurable but curable.

177. xxxx xxxx Member of the Public

Affected Comment:

Brother died from lung cancer at 50 years old. Diagnosed too late

Recommendation comment:

Lung Abnormalities Depicted with Hyperpolarized Xenon MRI in Patients with LungCancer should be standard part of screening

Step change in imaging, safe. Addon to existing MRI machines

US_FDA approval expected by Sept 22

[Www.polarean.com](http://www.polarean.com)

Alternatives comment:

Lung Abnormalities Depicted with Hyperpolarized Xenon MRI in Patients with LungCancer should be standard part of screening

Step change in imaging, safe. Addon to existing MRI machines

US_FDA approval expected by Sept 22

[Www.polarean.com](http://www.polarean.com)

178. xxxx xxxx Member of the Public

Affected Comment:

My mother was diagnosed with Lung cancer at the end of October 2020. At the time of diagnosis she had none of the current listed usual symptoms. My mother was a very active, healthy person who had not taken any medication throughout her life. She looked very well for her age of 78. She developed back ache and shortness of breath for a couple of years and had visited her GP on numerous occasions with the following symptoms: shortness of breath, a pain in her back and an extreme feeling of being cold even in very warm temperatures. Unfortunately her GP put it down to old age and advised to do a little exercise and rest when tired. She developed what the GP thought was a chest infection in October 2020 and was prescribed a double course of antibiotics. The antibiotics didn't work and she was sent for a chest x-ray and then for a scan which showed she had stage 4 lung cancer. The cancer had spread throughout her body and sadly she passed away on March 2021.

Evidence Comment:

Lung cancer is diagnosed when recovery is not an option. A screening programme needs to happen.

Discussion comment:

Screening needs to happen.

Recommendation comment:

100% yes. Too many cases are undiagnosed until it has reached stage 4+

Alternatives comment:

Look at other symptoms I know a number of people who have died from this terrible disease and none of them presented any of the symptoms listed.

179. xxxx xxxx Member of the Public

Affected Comment:

Yes it's affected a few friends

Evidence Comment:

Not to my knowledge

Discussion comment:

Screening ex smokers over 55 wouldn't have caught on of my friends' lung cancer – who is under 55 and never smoked

Recommendation comment:

It should – why? Screening saves lives. the argument here is obviously cost; and if you're screening mainly smokers then take the tax from cigarettes to fund it. More screening is obviously better than less screening. this should be a yes/no tickbox because surely it's obvious why.

Alternatives comment:

I do not know how else to carry out early detection other than screening for it.

Other comments:

Expand screening to other age groups / non smokers as part of a yearly check up would be amazing; and not just for lung cancer. I'd pay a one time or yearly fee for a piece of mind body screen once a year for sure.

180. xxxx xxxx Member of the Public

Affected Comment:

My mum has lung cancer which was only detected when she insisted on an X-ray. One of my close friends was also diagnosed a year ago. Please earlier detection is the key so screening is the way forward

Recommendation comment:

Yes – definitely (as above)

181. xxxx xxxx Member of the Public

Affected Comment:

I had lung cancer in 2014/15. I had no symptoms and only spoke to my doctor as an off the cuff remark about an uncomfortable ache in my chest. I am very lucky the Dr sent me for a scan and I was diagnosed with lung cancer. I am very grateful to my oncologist to still be here but maybe had screening been available, my cancer may not have been so advanced.

Recommendation comment:

Like many other cancers screening saves lives. I also had cancer of the cervix which was picked up by screening. I whole heartedly support regular screening for lung cancer.

182. xxxx xxxx Member of the Public

Affected Comment:

My Mum, Joan Rackliff, died suddenly at the age of 63 in 2003. She had been given a chest x-ray after having breathing difficulties a few days before. The doctors said it was just a chest infection, gave her antibiotics and kept her in hospital overnight as a precaution.

The next day she was dead. The shock, of course, was unbearable and even after all these years I am crying as I write this.

A post mortem was carried out which revealed she had lung cancer and the tumour had pierced her pericardium. None of the doctors had spotted the 6cm tumour in the x-ray.

If screening for lung cancer had been available then, my Mum may still be alive today, or at least would have had the chance to have some treatment before the tumour grew so large.

Recommendation comment:

I definitely think screening should be recommended. Other types of cancer are screened so why would you choose not to help people who may have lung cancer?

My Mum had her life cruelly cut short but a screening programme now could help hundreds or thousands of other people.

Other comments:

It shouldn't need to be said but A&E doctors and also GPs should be better trained at reading X-rays.

183. xxxx xxxx Member of the Public

Affected Comment:

Yes, I was diagnosed with non smokers lung cancer stage 4 in March 2021. With hindsight, I had symptoms in January 2020 but an ECG showed atrial fibrillation. I was medicated but no one looked further. A CT in January 2020 would have shown the disease.

Evidence Comment:

I now think that I should have been regularly monitored over the years. I have had pneumonia which lead to late onset asthma. My asthma improved but I always had heavy chesty colds – inhaler only used to help cold. I was not monitored. In the last few years I was breathless when climbing inclines but then I was always last up a hill! When it got worse and I had a feeling from time to time – an ECG showed atrial fibrillation but no one looked further – my cancer was missed.

Just before I was diagnosed, I had to be very firm with my GP to first get an appointment, then be seen in person and then to get an X-ray. If I had not my diagnosis would have been delayed.

I have an ex colleague who died of non smokers lung cancer before treatment could start.

Discussion comment:

Most other 1st world countries screen for lung cancer – why don't we screen?

My daughter is a Spanish resident and hence has to have private medical insurance. She automatically health checked each year including an X-ray for lung cancer screening. After my diagnosis she was told she would now be upgraded to an annual CT scan – Spain thinks you need screening.

Her sister lives in the UK and I think she should be able to sensibly access lung cancer screening on at least a semi regular basis.

I believe education of young people is key.

The population needs educating about the symptoms of lung cancer but also about the large and increasing number of non smokers with lung cancer. They need to be made aware that it is more common in females than in men and it occurs in young people. Educate in schools and general population.

Recommendation comment:

Definitely, time that the UK screened for lung cancer. It must be available to all and not just smokers as is sometimes suggested but that is out of date and totally unfair.

When and how often and under what criteria we should screen is the question. But we should definitely screen and the question is who.

I know that as with any screening program the problem is false positives. Education can help with this. Also education of what screening is helpful would encourage some people to use the private sector screening sensibly and helpfully – at the moment people don't know what is sensible and what is not.

Alternatives comment:

Air quality is very significant.

If screening of all is not viable then at the very least screening should be made more available through GPs. It must not be a fight.

Non smoker lung cancer must be made more understood by all.

184. xxxx xxxx Member of the Public

I was diagnosed 3.5 years ago with stage IV terminal lung cancer. I was lucky, although I didn't know it at the time, that as a non-smoker I was likely to have EGFR. At time of diagnosis it also transpired I had Mets to spine hip and brain.

Evidence Comment:

I was lucky to be diagnosed reasonably quickly although there was no evidence of disease on the x-ray. Disease was only identified on a CT scan and further identified on a PET scan.

Discussion comment:

Prognosis and life expectancy needs to be improved. When you are in your 50's and are diagnosed with lung cancer and at best you are told you only have 5 years it's pretty devastating.

Recommendation comment:

I think screening would be a good idea for those groups/sectors of the population who are unlikely to be identified as high risk. It is all very well screening high risk patients but you probably already know whether they have cancer or not what is more difficult to identify are those who are never smokers or non-smokers. It is important to use the appropriate tools to enable diagnosis efficiently and the best tool in the screening scenario would be CT scanners.

Alternatives comment:

They could develop or use blood analysis more often. I understand there is a desk top digital cell comparator that can identify potential cancerous cells which could be done in GP practice. The use of CT scanners would fast track diagnosis and cut the use of x-rays which we know don't often spot many tumours.

Other comments:

Development into blood analysis, cell analysis and genome testing could help enable earlier diagnosis. More importantly investment in the right tools such as CT scanners for diagnosis would enable earlier diagnosis. Education of the general practitioners that anyone can get lung cancer if they have lungs and that everyone should be referred if they have unexplained respiratory issues or unexplained pain in shoulders, back and/or hip.

185. [REDACTED] Member of the Public

Affected Comment:

Recently diagnosed with adenocarcinoma with EGFR mutation. Inoperable and incurable. Every day someone new gets given the bad news and the majority are not discovered until they are stage 4. I have been screened every year since 2014 when a routine heart scan discovered I had ground glass nodules in my right lung. In 2019 one nodule had grown in size and was found to be pre cancerous. My right middle lobe was removed and I was given the all clear. Further scans up to November 2021 were given the all clear too. December 2021 brought the devastating news that I had a stage 3 cancer. Better routine scanning must be put in place as anyone can suffer a lung cancer at any age.

Recommendation comment:

Routine Screening on a national scale must be recommended. One in two people will get cancer and the earlier it is found the better chance we have of living with it.

Alternatives comment:

A national campaign to recognise the symptoms of lung cancer. Asking people to see their doctor with a cough of more than several weeks is not enough. My symptoms were breathlessness mistaken in my case as an infection and treated with antibiotics. Excessive fluid was not recognised as being a symptom of lung cancer.

Better education for GP's.

Other comments:

The need to act quickly is paramount. My treatment was delayed so many times by admin staff not recognising the urgency of requests by different consultants at two hospitals for treatment to begin. The stress and anxiety this caused me was dreadful. Better communication between everyone involved must be put in place.

186. [REDACTED] Member of the Public

Affected Comment:

My mother sister & uncle all died of lung cancer & it was diagnosed too late. With Screening they may have lived longer than they did.

187. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with Stage lung cancer in June 2013 following an X-ray because I had had a persistent cough for several months. Unfortunately because of the position of the tumour I had to have a right pneumonectomy.

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

As screening programmes are available already for a range of cancers I believe that the addition of lung cancer to this may assist in early diagnosis which we know is the key to successful outcomes.

Alternatives comment:

Ensure that all GPs routinely refer people who have a persistent cough are sent for a chest X-ray and that the set timetables are adhered to, e.g 62 days to start of treatment

Other comments:

It's important that we destroy the stigma of lung cancer as being the fault of those who get it because they smoked. Screening for everyone would go a long way to address this and confirm that anyone with lungs can get lung cancer.

188. xxxx xxxx Member of the Public

Affected Comment:

Yes my dad passed away in march

Evidence Comment:

Yes scan showed cancer in scan in June but wasn't diagnosed till January too late

Recommendation comment:

Yes most definitely

Alternatives comment:

There not enough help given

189. xxxx xxxx Member of the Public

Affected Comment:

I lost my mum to this awful cancer. Screening could of prevented this. Not enough has been done by the government to increase the survival rate of this form of the disease. Now is your chance. Screening for other cancers... why not this one?

190. xxxx xxxx Member of the Public

Affected Comment:

Back in 2004 my husband became unwell with severe pain in his neck and shoulder area. Also had a cough and breathlessness.

Doctors prescribed painkillers. Eventually he was sent to a physiotherapist who advised him to push for hospital investigation. This was eventually forthcoming and a sharp eyed radiologist spotted something almost hidden which turned out to be non operable lung cancer. By this time he was unable to walk very far. He had a course of radiotherapy and the next step would have been chemotherapy. He was told it might give him another 6 months. He refused this which I respected. Seeing him deteriorate so quickly was heartbreaking. He died January 2005. He had been a smoker all his life. Maybe if there had been some form of screening the outcome would have been different. I feel strongly that this should be a priority

Recommendation comment:

I think screening should be recommended.

If cancer is caught early enough it could save lives

191. xxxx xxxx Member of the Public

Affected Comment:

My dad died a very painful and early death from lung cancer.

Evidence Comment:

N/A

Discussion comment:

N/A

Recommendation comment:

Yes as by the time it is identified in many cases it is terminal.

Alternatives comment:

Continuing to raise awareness about the impacts of smoking and vaping including secondary/passive inhalation.

Other comments:

N/A

192. xxxx xxxx Member of the Public

Affected Comment:

My husband died of lung cancer in February of this year. Until October last year he was, we thought, a quite healthy man. He had a chest infection and after a telephone consultation with the Dr he had to have a chest X-ray and bloods taken etc. The Dr rang back to say something had come up on the X-ray and I think we knew then that it wasn't good news. He had a very large tumour which was not operable and the choice was a matter of months with chemotherapy or a matter of weeks without. He chose chemotherapy but had

a long lingering death in the end. I stayed with him for four days in the hospital as he struggled to breathe but was at his side when he died.

Evidence Comment:

If there had been screening for lung cancer as a matter of course, the tumour would have been detected earlier and other steps could have been taken. He could have been still with me today. Instead, I will spend the rest of my life alone.

Discussion comment:

No

Recommendation comment:

It definitely should be recommended. Had we known earlier, my husband may have had the chance of an operation to remove the tumour. Instead he took 4 days to die in hospital with me by his side.

Alternatives comment:

What other alternatives are there. I do not know of any.

Other comments:

No. I think I have made myself clear with my comments above.

193. xxxx xxxx Member of the Public

Affected Comment:

I think lung screening is very important. My husband died from lung cancer only 2 months after being diagnosed. If he had been screened as a precaution like a lot of the other cancers such as breast cancer he may still be here today.

Evidence Comment:

Unfortunately the symptoms only showed up in October and gradually got worse. Not suspecting anything serious he didn't go to the doctor's until December at which time the wheels were set in motion for a scan.

Discussion comment:

Please seriously consider bringing lung screening in so other families don't have to go through the awful situation we did.

Recommendation comment:

I definitely think it should be recommended as it is heartbreaking to be told you only have 6-8 weeks left with your loved one.

194. xxxx xxxx Member of the Public

Affected Comment:

My husband who never smoked, died of lung cancer in Nov 2021 just after his 57th birthday.

He was never sent for early screening by GP as he was a never smoker and therefore was not given the chance to have preemptive consultation or treatment and was given asthma inhalers instead! Disgusted with the wait time to start treatment once he had been diagnosed at stage III.

Two tier system at xxxx xxxx for private and NHS made us feel like second class citizens.

Evidence Comment:

My husband should have been sent for screening like other people i know who are smokers. Gp assumed it was not cancer yet if he had been a smoker i am sure he would have been sent. Also at the xxxx xxxx they did not do a scan up to the neck area as we were told this was NICE guidelines, yet further cancer later found which had spread. I believe if he had been treated the same as a private paying patient rather than NHS which he had paid into, he may still be here. The medical authorities let him down and his orphaned children. Shame on them.

Discussion comment:

Screen everyone with symptoms of unexplained coughing, not just those who have chosen to smoke cigarettes.

Recommendation comment:

Of course it should be recommended.

Alternatives comment:

Provide proper scans post chemo. Provide enough treatment for patients and not phone them telling them that they dont have enough chairs.... all adding extra stress.

Other comments:

xxxx xxxx should not keep advertising its cancer success stories as a broad version and be honest about how most of their treatments are kept for their private patients. Disgusted.

195. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with lung cancer at the age of 31 years. A lifelong non-smoker. The road to diagnosis was painful and prolonged as I kept being told I didn't 'fit the profile' despite having many many signs of lung cancer. I am now living with a stage 4 diagnosis and the impact on my family, especially my daughter was just 2 when I was diagnosed, has been devastating.

Recommendation comment:

Routine screening should be available to anyone who has a close familial relative who was diagnosed with lung cancer below the age of 60 and a non-smoker. I fear for my daughter's future more than I can say in case this is genetic and she faces the same path as me, with no one believing her symptoms because she 'doesn't fit the profile'.

Your GPs and experts still on the whole believe you only get lung cancer if you're old and smoke. This isn't true and only by introducing a screening programme for those who fall outside of this group will you start to identify all the lung cancer diagnosis missed through blinkered poor diagnoses by GPs and start to save lives.

Lung cancer is the biggest UK cancer killer and it is criminal there is no screening programme in place.

I live in fear more for my daughters future than my own. My sentence has been cast but you can still save hers. Please, I beg you to reconsider this.

Alternatives comment:

A screening programme for those with close family diagnosed with lung cancer in younger years and as a non smoker is the only way to pick up genetic lung cancers. This is offered from breast cancer and look how many lives have been saved through early diagnosis.

Do not give my daughter the same life sentence I gave received.

Other comments:

Wake up and realise your doctors misdiagnose lung cancer day in and day out and this is costing lives and the NHS more money longer term as diagnoses are happening so late.

I 'didn't fit the profile' and we constantly misdiagnosed for over a year until it was too late for me. This will be happening right now in GP surgeries all over the country.

A CT screening programme for those with a higher probability is the only way forward.

196. xxxx xxxx Member of the Public

Affected Comment:

Profoundly. My husband was diagnosed with 'chest infections' between December 2011 and May 2012. He saw the same GP several times. When he saw a locum doctor in May the locum sent him straight to hospital for an x-ray. He was quickly diagnosed with Stage 4 non-smoker's lung cancer. Valuable time had unfortunately been wasted. Malignant fluid now filled my husband's chest cavity, making life-extending surgery impossible. My husband's gp said he was a 'wait and see' doctor – not a great way to treat any prospective cancer sufferers. He never even had an oximeter test to see if he was fully oxygenated; the doctor used to tap his back and say things like 'there's definitely air down there'. He was 52 when he died a long drawn-out death. Our family will never get over it. He was a brilliant father, husband and outstanding scientist who had much still to offer. A screening programme could well have helped him, found the tumour early and kept him alive.

Recommendation comment:

Yes, so that lives, often young lives, can be saved.

Alternatives comment:

Education. Making sure people realise that they don't have to be smokers or coughing up blood to have this dreadful disease.

197. xxxx xxxx Member of the Public

Affected Comment:

This is a condition that affects me – and on a daily basis. I get constantly breathless and have a sharp pain in my side that is caused by the irritation from the tumour. I wish I didn't have it or that it could be operated on but no such luck.

It has affected my everyday life and impacted on so many areas that leave me a tearful wreck.

Evidence Comment:

No – keep on with the research and never give up on finding a cure.

Discussion comment:

No.

Recommendation comment:

Screening should be recommended to ensure people don't fall through the net.

Alternatives comment:

No.

Other comments:

No.

198. xxxx xxxx Member of the Public

Affected Comment:

My father was diagnosed with lung cancer and 12 weeks later died. The early signs were excused by other factors and unhelpful investigations eg stomach by GP that declared he was cancer free. Therefore he went from the urgent pathway to a long waiting list to follow up and further assess. Hence the late diagnosis.

A robust screening would have potentially picked it up earlier and allowed him to have treatment that he so dearly wanted.

Evidence Comment:

Passive smokers appear to have been excluded from the screening proposal. I would ask if this is an important sector of society who actually choose to not smoke but may have been exposed through no fault of own or as a child on the home of a smoker? Surely they have a right to be offered screening as much as an actual smoker?

Discussion comment:

If LDCT screening as stated is cost effective compared to no screening then it brings likely value for money within a tight NHS budget, therefore should be recommended by NICE.

Recommendation comment:

Screening should be recommended as evidence shows likely to be cost effective compared to no screening. Early diagnosis brings chance of treatment and management of disease to potentially extend quality of life.

Alternatives comment:

Increased awareness of symptom. My mum now says my father had had a cough for a long time before seeing GP. Gp staff increased knowledge and immediate inclusion of investigations eg chest X-ray rather than single organ approach only. Bloods did not show anything.

Other comments:

Further research on one of the largest cancers across the world, to give more information for medical screening/ treatments.

199. xxxx xxxx Member of the Public

Affected Comment:

From being diagnosed with Lung Cancer in 2012 from having a persistent cough and having a brilliant Doctor, I was determined that this would not affect me fiscally or mentally if I had anything to do with this. I took on an aggressive treatment under the Covert trial 2012-2014 which was harsh but after having good

CT Scan results and everything seemed to calm down. 2015-2017 I needed more treatment, chemo didn't work as previously so went on new trial for Immunotherapy which sat better with my body and everything again seemed alright. In 2022 dots appeared in my body and this was not Lung Cancer I've had treatment Feb-Jun and feel good but this time it was a shock as I thought I was just living with cancer. Around me I have had a good support group of friends and family plus various organisations.

Evidence Comment:

I have been happy with what has been said in this review.

Discussion comment:

No

Recommendation comment:

Yes screening should be recommended. It is best to be told in the early stages of Lung cancer to get something done about it than leave it until it is too late and you lose your loved ones.

Alternatives comment:

To do something like the COVID-19 swab tests at the various sites for this around the country. It might be the stigma of going into a hospital to check if you have a cancer.

Other comments:

Make people that have been diagnosed with Lung cancer what they are entitled to in the way of financial help, palliative and other support as the shock sets in when first told and your mind is in such a turmoil you do not think straight. Also always have someone with you, being told on your own is too much to take.

200. [REDACTED] Member of the Public

Affected Comment:

I have stage 4 NSCLC. Diagnosed sept 2018. No symptoms except strange eyesight.

My mother and grandmother died of lung cancer and although a minimal smoker in my 20's was never considered as a possible lung cancer sufferer.

Recommendation comment:

Screening should be considered. This disease affects so many people many of whom are fit, young, women and non smokers.

Too often sufferers are diagnosed at stage 4 incurable. With screening possibly early stage and therefore curable lung cancer may be picked up.

Alternatives comment:

Earlier diagnosis. Gp's should be more aware that lung cancer can affect fit, young, non smokers as well

201. [REDACTED] Member of the Public

Affected Comment:

My sister Alexandra died in 2011 aged 45 of stage 4 lung cancer. She developed a cough in April 2011 and as this did not get better she was seen by her GP and prescribed antibiotics. Things did not improve and she was sent for a chest X-ray. She started coughing up blood and was admitted to hospital with pneumonia. In

May 2011 she was given a bronchoscopy and at the beginning of June she was diagnosed with stage 4 lung cancer. She had chemotherapy but developed pneumonia after the first dose and died at home on 3rd July 2011.

Recommendation comment:

I think screening should be recommended. Surely if detected early there would be better treatment options and more successful outcomes for people with lung cancer and their families.

Alternatives comment:

Better support and understanding. We had no idea what to expect or how ill my sister would be. Even though she was allocated a MacMillan nurse when she tried phoning she just got an answer machine and instead we relied on ringing the GP. No one told us how things would progress or how to manage symptoms. A proper support and educational programme for patients and their families who feel so lost and devastated while trying to deal with this dreadful disease.

Other comments:

Educate children about the risks and dangers of smoking. Improve peoples understanding of symptoms, prognosis and treatment options.

202. xxxx xxxx Member of the Public

Affected Comment:

Yes I have had lung cancer. I also have friends and family with lung cancer.

I was diagnosed with stage 1 adenocarcinoma.

This happened because my GP referred me for an X ray when I presented, age 62, with a cough of 3 weeks. It transpired this was due to a chest infection not the cancer. If I had not had the infection it would not have been found at that point without access to screening.

A lobectomy followed and no further treatment required. I lead a full and healthy life.

Recommendation comment:

Yes it should be recommended.

A comprehensive screening programme would save lives and also save the NHS and other section of public provision money by reducing the number of people with late diagnosis requiring ongoing, longterm treatments and life limiting health issues.

Other comments:

Simply instigate the introduction of a screening programme swiftly!
Also educate not just the public but health and care staff about lung cancer.

203. xxxx xxxx Member of the Public

Affected Comment:

A friend had lung cancer, I had breast cancer

Recommendation comment:

Yes most cancers caught early are treatable

Alternatives comment:

Support groups, stricter laws for tobacco and other carcinogenic products.

Other comments:

No

204. [REDACTED] Member of the Public

Affected Comment:

Yes

Evidence Comment:

No comments

Discussion comment:

I agree that large scale screening should only be done if the cost benefits are clear. Risk of unnecessarily harming people through false positives are important considerations

Recommendation comment:

Not recommended. Benefits do not clearly outweigh risks

Alternatives comment:

quick access to diagnostics and treatment. Better communication about treatment options.

Other comments:

No

205. [REDACTED] Member of the Public

Affected Comment:

Yes my mother

Recommendation comment:

Definitely should be recommended so it can be caught in time and treated

Alternatives comment:

Mandatory screening offered for people of a certain age, like breast screening is

206. [REDACTED] Member of the Public

Affected Comment:

My auntie was diagnosed my lung cancer after having a cough.

207. [REDACTED] Member of the Public

Affected Comment:

Yes a good friend

Recommendation comment:

Screening should go ahead too many people are diagnosed too late and screening would pick up a problem early with better outcomes

Alternatives comment:

People with the condition better access to hospice and end of life care. Better support services help with transport costs free car parking at hospitals etc etc

Other comments:

Support GP practices better

208. xxxx xxxx Member of the Public

Affected Comment:

In 1975 my husband watched his Grandfather die of lung cancer. Here we are 47 years later and still no screening process. My husband saw a friend die at Christmas with the same illness. In the 21st century it's about time there was. The Bowel Cancer screening has saved lives. Let's do the same with lung cancer please! You know it makes sense and will save money in the long term. After the past two years with COVID and 2022 politically let do something positive. Thank you for your time.

Discussion comment:

Why wouldn't the Government want to save lives!?

Recommendation comment:

The Bowel screening has saved lives. The Lung Cancer screening could do the same!

Alternatives comment:

We've cut back or eradicated cigarette advertising, lets do the same with vaping please. Prevention is better than cure.

Other comments:

Show school children films of folk dying in hospital from lung cancer. Show them it's not cool to smoke. Ban cigarettes from sale. Ok the government will lose the tax but it will be recouped from other places.

209. xxxx xxxx Member of the Public

Affected Comment:

Diagnosed December 2017 stage 4 NSCLC

Recommendation comment:

Earlier screening would have helped people as me

Alternatives comment:

Greater awareness Lung cancer seems the poor relation !!!
Generally people think it's your fault because you smoked
No I'm not a smoker or never have been

210. [REDACTED] Member of the Public

Affected Comment:

I have never smokers stage 4 lung cancer, had no symptoms until I noticed that on taking a really deep breath I couldn't get the final bit of breath. Went to a and e within one month and chest x ray showed a shadow, pet ct then confirmed in spine, hip femur and lymph nodes. As a runner and cyclist in my early 50's I had put some back pain down to age.

Recommendation comment:

Screening most definitely should be done as it would pick cases up much sooner.

Alternatives comment:

Any other measures should be along side screening. Lung cancer is still not promoted enough that non smokers can get it and never smokers lung cancer has is just not thought of as possible until it effects someone personally. If someone had said one day you will get cancer I would never have considered it would a lung cancer.

211. [REDACTED] Member of the Public

Affected Comment:

Yes my extremely fit 65 year old, never smoker husband died of lung cancer 3 months ago

Evidence Comment:

Why were non smokers also not tested? My husband was an extremely fit cyclist who had never smoked. He was diagnosed as stage 4 in 2020. I did not even realise that non smokers could get lung cancer, let alone that if someone did get it they may well only be diagnosed when it is too late. This does not feel acceptable in 2022

Discussion comment:

Anything that cuts the risk of someone losing a loved one so soon has to be a good thing but it feels unfair that only smokers should be tested. I myself(a non smoker) would take the test like a shotY

Recommendation comment:

Yes it should be recommended as the late diagnosis of this disease leads to such poor outcomes

Alternatives comment:

Early detection is vital personally I think the NHS should offer full body scans, which people could contribute to the cost of if able

Other comments:

Find a way to screen non smokers too.....they also get lung cancer

212. xxxx xxxx Member of the Public

Affected Comment:

I'm 46 and had only just got nails when I was diagnosed as Stage 4, no warning, it's had a devastating affect only life for me and my husband and our plans to have children were snatched away from us

Evidence Comment:

I went to the doctors numerous times with a cough and was continually told it was asthma, no X-rays no scans just given differ inhalers to try. By the time they eventually sent me for an X-ray it had spread to my spine and was diagnosed as stage4, beyond words!!

Recommendation comment:

Screening should definitely become standard practice not just for elderly, I'm 46 and one of my friends is 42 and also has been diagnosed too late, GPs need to be much more aware that cancer is not just for older patients, we are non-smokers but it's because we don't 'meet the criteria' doesn't mean we shouldn't be given every chance to live! Early diagnosis would have given us a much better chance.

Alternatives comment:

Much more online awareness needed, GPs need to have the information/equipment for early diagnosis

213. xxxx xxxx Member of the Public

Affected Comment:

Not affected me personally but friends have died from lung cancer.

Evidence Comment:

Unknown.

Recommendation comment:

Should be recommended. Preventative screening is cheaper than curative treatment. Patients' cancer would be caught before becoming too advanced and more likelihood of survival or longer life.

214. xxxx xxxx Member of the Public

Affected Comment:

My husband died from lung and metastatic brain cancer in November 2006. Two GPs and an ENT consultant wrongly diagnosed him with inflammation of his upper respiratory tract and prescribed PPIs. He was a Captain in the Merchant Navy on large gas tankers and away at sea for up to five months at a time. I requested a chest x-ray and was told it was unnecessary. I KNEW something was wrong with my husband from the strange persistent cough I noticed whenever he telephoned me. He went back to sea with me begging him by email to arrange a chest x-ray and after some weeks he finally got one in Buenos Aires where he was told he had a tumour on high right lung. He had to wait for a replacement officer to arrive and then came home to see a lung physician in Sunderland who did a bronchoscopy. On that day he told my husband that he had stage 4 lung cancer and had a 40% chance of living for up to five years. It will stay with me as long as I live. The NHS let my husband down. I will never forgive all those who did not check him properly and would not refer him for a chest x-ray.

Recommendation comment:

Screening should be recommended. For 2 GPs and an ENT consultant to wrongly diagnose my late husband is an absolute travesty of justice and the ensuing delay in being refused screening her and for him to eventually have a chest x-ray in Buenos Aires may well have contributed to his demise.

Alternatives comment:

Doctors do not listen to patients enough! People know how they are feeling, and are often very in tune with their bodies. Just because a GP thinks something is unlikely to be the problem has so often ultimately caused someone's death, just as cancer in very young people is often missed because it is unlikely! Anything can happen to anyone of any age. I have respect for the medical profession but there is no question that doctors kill people – just as they save people. Many doctors become too arrogant to see a situation from the patient's perspective.

Other comments:

Perhaps smokers should have chest x-rays as routinely as women have mammograms. A chest x-ray is a speedy process, not very costly, and might have saved my husband's life. With cancer, time is of the essence. My husband died in 2006 at the age of 58 – I will never forget what he went through. The ENT consultant who diagnosed him with inflammation of his upper respiratory tract telephoned him when she heard about his cancer diagnosis. The two GPs said absolutely nothing. Anything that enables an early diagnosis has to be a good way to go.

215. xxxx xxxx Member of the Public

Affected Comment:

I am Executive Chairman of Cizzle Biotechnology Holdings PLC, (www.cizzlebiotechnology.com) an early stage lung cancer detection company however I am submitting my comments from personal perspective because I was diagnosed with stage 1 melanoma on my scalp some years ago. It was detected incidentally when visiting a clinic for an in situ melanoma on my chest. If it had not been detected I might not be here to complete this form. In many ways melanoma being visible on the skin is much easier to detect than for those with non symptomatic lung cancer. That more lives are lost through lung cancer than other forms is highly indicative that effective large scale screening is needed to detect lung cancer early before it becomes symptomatic and when surgical resection or radiotherapy can make a difference

Evidence Comment:

One of the reasons for the current recommendations not to screen for lung cancer was the limited evidence of an available test which would be suitable for use in a screening programme. It appears that since little reference was given to the importance of biomarkers that this perception has not changed. Yet it is known that the CIZ1 B biomarker can be detected in blood in relatively high concentrations with proof of concept assays giving 95% sensitivity (Coverley D, Higgins G, West D, et al.

A quantitative immunoassay for lung cancer biomarker CIZ1 b in patient plasma. Clin Biochem. 2017; 50: 2017). This is now in commercial development.

Not having access to a low cost simple blood test that has possibilities as a POC tests such as a LFT can cause the conclusion that "Overall, lung cancer screening is likely to be more expensive than treating people through the current symptomatic pathway of diagnostic testing" to be wrongly weighted. The danger being that symptomatic testing will not adequately detecting cancer at Stage 1.

Discussion comment:

It is pleasing to see that "Given the parameter updates and minor structural changes presented in this interim report, ENaBL estimates that screening for lung cancer with LDCT would likely be considered a cost-

effective intervention” a simple blood test that can detect stage 1 lung cancer could improve the outcomes of LDCT and perhaps provide a lower cost, scalable solution unhindered by critical infrastructure where CT scanning is less available, exclude false positives and through early surgical intervention improve mortality rates.

Recommendation comment:

The availability of a simple blood test for detecting stage 1 lung cancer is a simple and cost effective tool for mass screening of at risk individuals. Reducing false positives arising from current CT protocols will remove significant numbers of people from the cancer care pathway, prevent unnecessary patient concern and possible mental health issues, save on health professional time and resource and most importantly save lives.

Alternatives comment:

It depends on how screening is defined. Clearly patient education is important but fails if there are a lack of symptoms when patients refer themselves for clinical intervention.

At the end of the day a reduction in smoking and all the health campaigns that go with that helps because prevention will always be better than cure.

Other comments:

I believe there will be significant advances to early lung cancer detection over the next few years. Whatever the conclusions of this consultation process the future must be more interactive, and as much as possible be open to change at more regular intervals to reflect the actual data as its processed.

216. xxxx xxxx Member of the Public

Affected Comment:

I have friends and their families who have suffered from cancers of various types and therefore I believe that we should be doing all we can to detect cancers as early as possible if the technology/tests are available.

Evidence Comment:

I believe that use of a cost effective simple blood test that has been devised by a UK company can alleviate suffering and ultimately loss of life as it can detect lung cancers at a very early stage. I have read that once symptomatic many sufferers are not likely to see out a further 5 years of life.

Most people become aware of a lung issue during CT scans for something unrelated. If these people could have a simple blood test to confirm or not a cancerous growth then, if positive, a much more effective targeted treatment can be used before they have become symptomatic thus saving money and reducing suffering long term. Likewise if negative then medical services, costs, would be reduced as they would not require further ct scans etc to monitor the issue.

Another cost effective way would be to screen people who are high risk (ie smokers) on a yearly basis. If caught before becoming symptomatic, again cost effective treatment could be administered reducing the burden on the system as they have been caught before becoming symptomatic.

Discussion comment:

I believe screening should be considered as a cost effective early stage lung cancer test is becoming available. The UK company, through the large iCCAMT group in China, are beginning a trial there in the coming months. They are also in the process of securing similar in the USA. Both these countries have seen the potential cost savings and health benefits of using this test to detect lung cancer at an early stage both through potentially screening people at high risk and for those who show up abnormalities during scans. It

will save lives and be more cost effective for health services. They are a UK company using brilliant scientists at the University of York.

Recommendation comment:

I think screening should be available to those who show up abnormalities during scans and potentially, on a yearly basis, for people who are at a higher risk of suffering with lung cancer. It would save lives and be far more cost effective to confirm/or not cancer after CT scans and catch cancer before symptoms begin.

Alternatives comment:

Once someone becomes symptomatic the prognosis is not great therefore early detection would be more effective and if targeted correctly could alleviate a lot of suffering as more people would be treated before becoming symptomatic and may go on to live full lives without ever having to suffer from it. As smoking is becoming less socially accepted, targeted adverts and other incentives to lead healthier lifestyle may, with good screening, go some way to almost making lung cancer a disease of the past.

Other comments:

None. Thank you for the opportunity to share my views. A targeted blood test that can detect early stage lung cancer would be very advantageous to health and be very cost effective verses the long term costs of extra ct scans, less targeted treatments etc and more likely palliative care towards end of life.

217. xxxx xxxx Member of the Public

Affected Comment:

Yes my husband Kev passed away in October 2017 after being diagnosed with stage 4 lung cancer at the end of March that year.

I am still grieving, this disease completely has turned my life and family upside down. When I think I have turned a corner and think I'm feeling stronger I get flash backs to awful times during the weeks and months before Kev got his diagnosis.

Evidence Comment:

Opportunities were constantly missed to give an early diagnosis.

Kev presented to the GP with shoulder and knee pain he was told wear and tear. Little later on presented at GP's with pain in side and back following experiencing dreadful pain the night before. He was given Ibuprofen and omeprazole. Later that day admitted to hospital in pain. Xray showed a shadow and he was diagnosed with pneumonia. he was in hospital 8 days. On his day of discharge I spoke with a Dr looking after him to express my concern as I knew he was not right.....her words to me were....your husband is a fit man he's had a deep pneumonia.

The week end after his discharge he was admitted with pain again...this time told he had blood clots on his lungs.

The following week end he was in with an Infection

Then the next admission they said he had acid reflux sent him off with omeprazole.

We spoke/ saw GP and his consultant 6 weeks after his 1st admission, we said how Kev wasn't improving

And had started losing weight and the only answer we got was that having a pneumonia takes a long time to recover from.

By this time I was very concerned and rang our GP's to ask for help to arrange a private CT/MRI scan...I actually said to him please help me I think my husband has cancer. He told me to take him down on Friday to see him. He listened to his chest said not necessary for the scans and he would arrange more blood tests. On the Sunday following the appointment Kev had a stroke. He was admitted again, he was in 4 weeks this time, he became increasingly short of breath, fluid was accumulating around his heart. This was ignored all day and night. The next day it was an emergency, the fluid needed draining, while the Dr was performing this he punched his good lung.

From the fluid Non small cell adenocarcinoma Lung cancer stage 4 was diagnosed.

From end March to 10th May Kev waited to start chemotherapy.

A man who had never been in hospital before had started presenting at A&E ever week why wasn't that a red flag!

Discussion comment:

Because Kev had stopped smoking years before and he didn't look poorly at the start and seemed strong cancer was not a consideration.

How wrong was that.

Recommendation comment:

Definitely should be introduced.

If Kev had had proper screening at the start who knows where we would be today.

He wasn't given CT scan at the beginning of his illness.

Alternatives comment:

Better training for doctors.

Make them more aware of other symptoms associated with Lung Cancer other than cough....kev didn't have a cough

Start by looking for cancer and work down instead of looking for the less serious illnesses first as they do at present.

And listen to their patients!

Other comments:

Put awareness programmes on the television, in the media, make people aware of other symptoms of Lung cancer. other cancers are talked about so much more.

Let's lose the stigma.

Get People to realise it's not only smokers who get this awful disease.

Stop people always asking the question 'did he smoke' as if its the persons fault.

People who sadly get skin cancer do people ask did you sit in the sun!!!

218. xxxx xxxx Member of the Public

Affected Comment:

Within the family I lost my Brother in Law to Lung Cancer and a parent of a close family member.

Discussion comment:

Screening only made available after evidence based findings are reported is time consuming therefore leading to valuable time being wasted.

Some clinical trials have not been completed, Why?

Recommendation comment:

I consider screening should be routinely offered to any adult presenting to a GP/A&E/Hospital admission with one or more symptoms which potentially could be lung cancer. Screening is available for other health conditions and cancers however for lung cancer sufferers this is not the case. Why? is there any criteria where lung cancer should be considered less important/unimportant in comparison to other severe illnesses?

Lung Cancer has in the past had stigma attached to it in some areas of the medical profession and opinion held by some professionals that somehow this disease has been self inflicted if a previous or past smoker has contracted the disease, surely such out dated attitudes no longer plays any part in the successful or alternative outcomes for patients struggling with this illness. It is widely known that smoking does play a major part in this condition however other causes are responsible for others, standardised screening for all adults would mean that everyone would be given a chance of early diagnosis and increase the success rate of recovery in part or extended life expectancy and outcomes.

Alternatives comment:

Screening has to be a first starting point to diagnose Lung Cancer, this then supported with suitable medication, life changes, support networks and support groups would allow patients to feel valued within society and to allow them autonomy to help themselves manage and work alongside medical professionals to work towards a positive outcome.

219. xxxx xxxx Member of the Public

Affected Comment:

My father was diagnosed in 2015 with Small cell lung cancer. By the time he was diagnosed, his tumour was already too large to operate on. He had to endure months of chemo then radiotherapy, during which time the tumour shrunk but never completely disappeared. It was horrible for dad, knowing her would never be completely cured of this awful disease. He went from an active 75 year old man to a shell of his former self once the cancer had spread to his spine and bones. We watched him pass away at home on New year's day 2017, something that will stay with me for as long as I live. Knowing that maybe if screening had been available to him, the tumour may have been found sooner and at a time when it could have been removed with surgery, allowing him more time with is all and especially my mum who struggles every day without the love of her life, is heartbreaking. Please consider the screening programme, it could be a loved one of yours one day, something I wouldn't like to know that anyone has to live through and with for the rest of their lives.

220. xxxx xxxx Member of the Public

Affected Comment:

I have lost three family members from both my paternal and maternal family to this awful disease. I also have watched my daughter in law lose her 50 year old father (non smoker) to lung cancer. My 68 year old brother in law also died. I believe screening would have assisted greatly had it being available.

Recommendation comment:

Screening is offered for many other cancers and therefore I consider the same opportunities should be afforded to lung cancer.

Lung cancer can be hard to diagnose and by screening it would catch those cases that are in the early stages and would otherwise go unnoticed until the disease was too advanced to treat.

221. xxxx xxxx Member of the Public

Affected Comment:

I think it is very important that screening takes place. I have relatives and close friends whose lives have been saved by screening.

Especially, when companies such as Cizzle Biotechnology offer low cost solutions in the form of blood tests. The Gov and NHS should be offering either this to all people over 40 or Radiology related scanning on a regular basis.

Cancer is a killer and preventative measures such as screening via blood could save the Gov and NHS millions

Evidence Comment:

N/A

Recommendation comment:

Yes, screening should be recommended.

I have relatives and close friends whose lives have been saved by screening. The heart ache and pain caused through cancer on the patient their families can be avoided with regular screening.

The tests offered by companies such as Cizzle Biotechnology are low cost solutions in the form of blood tests. These are vastly cheaper (a blood test is a fraction of the cost of a MRI or XRay type scan).

Testing in the form of Cizzle bloodtests could result in lots of patients avoiding the need to be tested with more harmful and expensive radiology scans.

The tests are also considerably faster as could be tested in the regular blood test way and can be performed by a less specialist nurse. There would be no waiting for a scan/xray or the trauma and mental health damage of waiting to find out.

Regardless of the approach the Gov and NHS should be offering either bloodtesting with biomarkers to all people over 40 or radiology related scanning on a regular basis.

Cancer is a killer and preventative measures such as screening via blood could save the Gov and NHS millions. The much higher cost of treating late discovered cancer compared to the much cheaper early stage cancer is a factor.

Alternatives comment:

Companies such as Cizzle Biotechnology offer blood testing with biomarkers which can identify cancer in the lungs and other parts of the body.

Other comments:

CIZZLE BIOTECHNOLOGY

222. xxxx xxxx Member of the Public

Affected Comment:

Cancer effects everyone

Recommendation comment:

Yes it Saves nhs time and money

223. xxxx xxxx Member of the Public

Affected Comment:

My dad had lung cancer and sadly died of the disease.

Evidence Comment:

My dad seemed to be treated for conditions that the cancer was causing and not the root cause, only when the cancer had spread to much was he diagnosed with lung cancer.

Recommendation comment:

I think screening should definitely be recommended. If you can find any problems early it give the person a much better chance of fighting the disease.

224. xxxx xxxx Member of the Public

Affected Comment:

Mum died kf lung cancer.

Evidence Comment:

I would recommend you research Cizzle PLC, a UK company with a groundbreaking early detection cancer blood test proposal

225. xxxx xxxx Member of the Public

Affected Comment:

My father was a heavy smoker, he died of a weak chest, but not lung cancer. However 35,000 people die each year in the UK from this cancer.

Recommendation comment:

Yes, screening should be done. Have a look at Cizzle Biotech. This company has gained patent protection for its core technology and has developed a laboratory test, which has been used to validate the use of the CIZ1 B biomarker to detect lung cancer. The test is underpinned by 15 years of grant funded basic research into CIZ1 form and function, and its relationship with cancer. This has shown that CIZ1 is part of the nuclear structure that controls gene expression. A variant form, CIZ1 B is produced by lung cancer cells and can be exploited to detect lung cancer.

The company's focus is the early detection of lung cancer because of the high false positive rates associated with low dose CT scans. The test is intended to address a clear unmet clinical need – the early detection of lung cancer, when curative surgical resection is possible.

226. xxxx xxxx Member of the Public

Affected Comment:

I have lost grandparents to Lung Cancer.

Evidence Comment:

I would consider not just screening smokers.

Any profession that carries a risk of inhalation of particles.

For example someone that works in the textile industry could inhale nylon fibres. Leading to pulmonary fibrosis. Later largely leading to Lung Cancer.

Other professions that involve building or vehicle maintenance or construction regardless of PPE also carries a risk.

I know you tried to cover this in question one but I ask is there an unexplored bias in your theory? There would be a strong correlation to the type of environment that men work in vs women with there being far more vehicle and construction jobs and men working in them.

Discussion comment:

Using LCDT should be done with a companion diagnostic. A blood test.

One can then compliment the other. A company called Cizzle Biotech has a test in lab stage development. They are currently outsourcing reagent manufacture and then ELISA test manufacture. In the lab, this test achieved an extremely high level of accuracy.

Using two methods together will ensure that the patients are more likely to be put on the correct pathway before undergoing potentially expensive and unnecessary invasive procedures that carry risks of physical and mental harm.

The test could also be used in other environments for where there is potential of an accidental discovery of lung cancer. In A&E wards for example. Or if a patient doesn't want to absorb 6 months worth of "natural" radiation in one hit, they might consent to a blood test only.

I am aware of other blood tests for presenting patients and know their current accuracy to be very low. Effectively a coin toss.

Mobility and locality to a hospital could be an issue too, hence the low response rate from direct mail, where as a community nurse or clinic may yield a better response in screening. Walking distance and less pressures associated with a hospital environment.

Recommendation comment:

Yes but a companion diagnostic is needed. Or it would be better to use a diagnostic before using LCDT. The results do not suggest alone that there was a significant reduction in mortality and that it was difficult to balance the benefits vs the harms caused by the process. Hundreds of patients in trials had to be screened to save a life.

A diagnostic assay would prevent many barriers associated with the testing process. Small, portable, easy to use and transport. Appointment times for skilled professionals would be cut meaning a greater cohort as defined in an earlier question could be screened with a more focused and less costly and more patient friendly approach.

Alternatives comment:

The only other feasible alternative is to have the diagnostic from Cizzle in place in local clinics or A&E wards.

Patients will naturally present with chest pains, persistent coughs or other issues instead of responding to a screening programme.

Other comments:

The NHS needs to open up fully and manage patient access in a way that it never has before.

Appointments are often disjointed and uncoordinated. Non personal and lack the aspect of care that's needed.

Each and every patient, regardless of whether it is a minor surgery or major surgery should have a patient coordinator looking after them and chasing up referrals. GPs should do this and could facilitate screening. The way surgeries are compensated for having patients on record needs to change.

I can directly compare paying privately for an operation vs three years of seeing various people in the NHS. Privately I saw one person and the whole process of referral, surgery and aftercare was 3 months. In the NHS I had three years of going from pillar to post with no progress, seeing people who had no idea why I had come to them whilst referrals in other instances simply got lost. And this was before covid.

You now have an even greater backlog and large scale LCDT screening could add to it. Bio marker blood testing first could be a much better option.

227. [REDACTED] Member of the Public

Affected Comment:

Yes family members and friend ms have suffered from this condition

Recommendation comment:

Screening is expensive and time consuming and very important but there are other options such as simple blood tests that are being developed. especially exciting is the work of Professor Dawn Coverley at the University of York and her company Cizzle Biotechnology

Alternatives comment:

Via a Simple blood test such as what has been proven at the University of York with the

CIZ 1 protein variants and is currently being tested for commercialisation

Other comments:

Visit their website and review the technical paper and other documents

<https://cizzlebiotechnology.com/app/uploads/2021/05/Technical-Report.pdf>

228. [REDACTED] Member of the Public

Affected Comment:

Yes my husband died from lung cancer. He had never smoked and by the time it was diagnosed it was stage 4 and sadly too late to save him

Recommendation comment:

Screening should be recommended

Alternatives comment:

More research into why people who have never smoked develop lung cancer

Other comments:

Wider screening will hopefully pick up cases earlier and give more people a chance to survive

229. [REDACTED] Member of the Public

Affected Comment:

Lung cancer

Recommendation comment:

Cizzle biotech have a blood test that will avoid evasive therapy ti's should be considered

Alternatives comment:

Investing in new technologies like this which will improve patients health and save the NHS money

230. [REDACTED] Member of the Public

Affected Comment:

Yes my farther

Evidence Comment:

Yes- there is a simple blood test with trials planning in China by a company call cizzle biotech
A uk listed company

Discussion comment:

Please keep your eye out for cizzle biotech a uk based company

Recommendation comment:

Yes if there is a reliable simple cost effective test (cizzle biotech)

Alternatives comment:

There is no alternative apart from diagnosis early

Other comments:

No

231. [REDACTED] Member of the Public

Affected Comment:

My husband was diagnosed with Stage 4 Non Small Cell Lung Cancer in March 2020, age 50, after being admitted to A&E for an unrelated symptom. He was otherwise fit & we thought healthy, cycling 150 miles a week. The chest X-ray was taken as a last check and showed a shadow on his lung. Further scans in the

following weeks showed cancer had spread to lymph nodes and brain. Anyone with lungs can get lung cancer and many are being diagnosed at a late incurable stage at a very young age!

Recommendation comment:

It should be recommended at a young age as so many patients have no symptoms of lung cancer until it is at a late incurable stage. Earlier diagnosis has a much higher chance of successful curable treatment.

Alternatives comment:

More acknowledgement & being less stigmatised & associated with smoking. It can affect anyone and it is not just older adults.

232. [REDACTED] Member of the Public

Affected Comment:

When I was 24 my mother passed away from a metastatic adenocarcinoma of the lung, aged 62. The secondary growths appeared in the brain and affected bones and lymph nodes. She was diagnosed in May 2017. This was after trips to the doctors for feeling faint and partial collapses (2-3 months prior), she was told to wait for a scan, this never materialised. When driving one day she lost the use of one side of her body and was taken to hospital, they found a brain tumour causing that, then days later to be confirmed as cancer and the originating location of the cancer, the lung. She was given 6 months to live. Radiotherapy was carried out with 1 round of chemotherapy but that was soon ceased after the negative effects of it outweighed the option of giving up on it and enjoying the last few months of life. She actually surpassed expectations and lived for nearly 12 months after diagnosis. The last 6 months painful though as the cancer caused breaks in her spine leaving movement restricted. She used to smoke when she was younger, she smoked for a period of 10 years before she gave birth to me. During her diagnosis and treatment there were many hospital & doctor visits, a vast amount of medication and support equipment such as a replacement bed and walking frame and we purchased an electric scooter which she loathed and a nebuliser. I believe she had around 3-4 stays in the hospice and also visited the day hospice weekly. The uncertainty in the cancer was clear, I received several phone calls during the 12 months, all events where she had been expected to pass away, a few deemed far too early, but of course not until my last phone call did she actually pass away. I won't ramble on but this has destroyed mine, my father's and my uncle's lives. I also lost an ex-work colleague who again had headaches and by the time the cancer was found, it was too late, diagnosed February 2020, he passed 2 months later.

Evidence Comment:

The report suggests, that in some cases, people will die from other causes before lung cancer is even detected. I appreciate some cancer can grow for a lengthy period but if this is the case why are people dying before diagnosis and quickly and unexpectedly weeks after diagnosis. Yes people may die of other things before cancer gets them which is why a suitable age cap at what you have suggested seems reasonable. There is no way that you can say to that many members of the population don't worry about screening you'll probably die from something else before any cancer gets you..

The report states; "A certain proportion of people with preclinical lung cancer in Stage III or IV will die from lung cancer without first being diagnosed" but then the report states "The probability of dying from undiagnosed lung cancer (very rare)". If lung cancer is growing with no physical symptoms present until stage 3/4 then it is incorrect to say there is no hazard from dying whilst undiagnosed. If it was diagnosed at the start of growth they probably wouldn't be dying from it. Diagnosing only tends to equal death because you have not done anything hence what the program is suggesting about catching it before it becomes terminal. Those that die from lung cancer without first being diagnosed will be reduced because those are

mainly the people stage 3+ and this programme is designed to catch it in the earlier stages, not prevent it entirely...

Discussion comment:

The reductions in lung cancer mortality are not a small figure and neither are the 5 year survival figures. That's a significant number of people that are kept alive rather than dying. Lung cancer survival is seriously underestimated and until the screening is implemented or trialled, you aren't going to have the real numbers about survival rates, which I think, will be greater than anticipated. As I have said above my mother lived for twice as long as expected, should she have continued with chemotherapy against doctors' recommendations, could it have been longer?.

I understand there is a concern around the administration costs to implement such a thing, to me the screening would be the same as a smear test, you get reminded and you take it or leave it. Programme administration costs are minimal however I do see/accept a difference when it comes to triage telephone calls however I would not expect the programme to have to go to these lengths to persuade the general public to have it done, the option is there and they take it or leave it. If the screening programme went ahead, no matter the frequency, it is likely, similar to the smear test/flu-jab, there are going to be individuals who refuse your offer. With this in mind, costs will be saved on those who may be offered it, but never physically go for the screening thus reducing the cost implications suspected.

Recommendation comment:

I believe screening should be recommended. As above I have mentioned the administration costs and resource costs by stage at diagnosis and type is still high at stages 3 and 4, its hardly significantly cheaper to avoid/delay diagnosis until this point and so screening should be implemented, it will give us early detection of lung cancer.

Alternatives comment:

For me personally, if there were quicker and smoother processes in the NHS in general, lung cancer may not go on undetected for so long. On the two deaths I have mentioned above, on both occasions, scans were waited on for months by the individuals. I appreciate some cancer grows slowly but on some occasions, if the scans had of occurred quickly after the individual sensed there was an issue, the cancer would not have gone undetected for as long. Again, early detection is crucial. Also, even booking doctors appointments are hard, which is one some people sadly give up, again not your job to go chasing after people to help them but there are clearly processes in the NHS that need improving, speed is crucial and earlier doctors' appointments and scans, would assist in the process of detecting lung cancer and other diseases/illnesses quicker.

Other comments:

If you are confident it is such a lengthy time between growth/affecting the individual, then maybe the screening does not have to be on a consecutive/annual basis? The smear test for women has recently been increased to 5 years, once the reasoning behind it was explained it, there was a reduction in the backlash against the original decision.

I agree screening for lung cancer will lead to incidental findings in some cases, one would not expect a medical professional to ignore those just because that's not what they were looking for on that particular occasion. Yes that could be treatment for other things is required at a cost but it could also mean that yet another disease/illness is caught at an earlier stage and thus not only saved life but reducing the cost of end of life care/ trying to keep someone alive when you know they are dying. These costs, lung cancer or not, surely are higher as the report has suggested, than it is to look after the patient during earlier stages of the diagnosis who has a positive prognosis. Some of the expenses I personally witnessed' my mum had several scans after the diagnosis to monitor the growth and provide her with a life expectancy figure,

chemotherapy costs, radiotherapy, countless medications equipment such as bed for the home, walking frame, cane, free wigs for when the hair loss was expected, nurses coming to the home, several visits to the hospital, other countless breathing issues and inability to feed/look after one's self led to home care visits, paramedics attended the house when they thought she was dying several times and of course all the doctors' appointments. I believe the cost of screening which catches the disease earlier is cheaper than looking after the patient during the later stage of the disease with the costs I have just described.

233. xxxx xxxx Member of the Public

Affected Comment:

Being diagnosed with NSCLC was terrifying and due to position although contained was inoperable. I had radiotherapy with curative hope and a little chemo but it spread to the Pleura. I was so unwell and had numerous chest infections. I have Metexon 14 and after immuno that only worked for a few months I've been on a very successful phase one trial for a year.

I have been aware of tepmoninib and capmatanib both of which have been approved by the FDA but hadn't yet by NICE. I'm happy one appears now to have been approved as a treatment for the mutation I have.

Recommendation comment:

I think screening for lung cancer is long overdue.

It's the biggest killer, more than breast prostate and bowel combined yet they are screened and not lung cancer. It is also affecting more

And more young women who have never smoked and the myth that it's an old smokers disease is outdated and needs to be dealt with via education.

Its not 'your own fault' no

More than bad diet is to bowel cancer.

Alternatives comment:

The importance of screening is to catch the disease earlier when it is more successfully treatable

Other comments:

Increase public awareness of the danger of lung cancer not by No Smoking ads but by teaching people it can happen to

Anyone

234. xxxx xxxx Member of the Public

Affected Comment:

My husband died of lung cancer aged 48 after a late diagnosis. My mum died of lung cancer at 54 after a late diagnosis. My grandad died of lung cancer in his mid 60's after a late diagnosis. Lung cancer screening could have saved one of them. Or all of them.

Recommendation comment:

Absolutely Recommended. Lung cancer is almost always diagnosed too late. By the time patients have severe enough symptoms to get the tests they need the cancer has often spread. Screening could bring forward the diagnosis time. It could save lives.

Alternatives comment:

Educate all GPs and doctors. My husband was told by his doctor he wasn't tested for lung cancer, despite numerous visits with a bad cough, because he was a young non smoker. My mother was told she had a chest infection then sinusitis. She begged for a scan but was refused. Even though she was previously a smoker. Provide more training so every doctor knows not just old smokers get cancer. My husband saw numerous doctors, attended A & E, and had a stay in hospital and still no one tested him for lung cancer. Even though his main symptom was a cough. And he had lost weight. And he was really tired. And it had been going on for months. How can this still be happening? How could not one of those doctors work it out? Make sure every doctor is fully aware of all lung cancer symptoms. Send them on courses. Give them the facts and figures. Educate the public. Ensure that every one knows symptoms to watch out for.

235. xxxx xxxx Member of the Public

Affected Comment:

Yes I was diagnosed with Stage 3 NSCLC in April 2020. My cancer was detected incidentally whilst having a routine chest X-ray. I presented with no obvious symptoms.

Discussion comment:

Lung cancer is the biggest cancer killer in the uk. Yet there is no national screening program in place. Why? The biggest cancer killer yet the most under-funded. Why?

Over 70% of patients are diagnosed at stage 3-4.

Earlier diagnosis is needed to save lives and bring better outcomes,

Recommendation comment:

Yes absolutely screening should be recommended. Screening saves lives. Just as screening for breast and cervical cancers saves lives.

If a screening program was in place then perhaps my lung cancer would of been discovered earlier not at stage 3.

236. xxxx xxxx Member of the Public

Affected Comment:

My father died from Mesothelioma. He worked with asbestos in the 1960's onwards in the electrical trade. He should never have been exposed to asbestos, especially when the UK government were made aware of the dangers of being exposed to this product for several decades!!! This product should have been banned as soon as the dangers were known. As a family, we lost our Dad far too soon. His lungs and eventually whole body was destroyed by this preventable disease. More needs to be done to help diagnose this lung disease, treat it and eventually find a cure. Detecting lung disease early is a must, especially as there is now an operation available for some Meso patients when the disease is contained within the lung,

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

It should be offered. My Dad might have had more of a chance had he been offered regular lung screening. After the Covid pandemic there is likely to be more lung issues that could be detected early.

My Mum has bronchiectasis and having had Covid, the scarring on her lungs has worsened. Lung screening will help identify more lung issues and hopefully prevent further damage by treating issues early.

Alternatives comment:

Research into cures would be a starting point, but many lung conditions are found by a simple scan. More complex conditions such as mesothelioma need MRI/CT scans but screening would be a good starting point.

Other comments:

As above

237. xxxx xxxx Member of the Public

Affected Comment:

My partner died in February from lung cancer, he was diagnosed in January!! Had he been screened we would not be in this awful position, we had no idea he was ill. he had non small cell as well which isn't as aggressive as single cell.

I know of many who have found out they had lung cancer when it was too late. Given now that many attribute shortness of breath and cough to covid it long covid how many people are going to die. Screen is imperative to prevent death. My partner was 56!!

Evidence Comment:

Cancers are screened why is lung cancer different?

Alternatives comment:

Awareness,

238. xxxx xxxx Member of the Public

Affected Comment:

My wife has now had it confirmed she has stage 4 lung cancer. This is after showing hardly any symptoms other than a cough which we had put down to the remnants of a bout of Covid. Also some mild breathlessness which was put down to lack of fitness. We are now fighting for treatment to begin from a very busy NHS. Screening to catch this earlier will save lives.

Recommendation comment:

This can be a cancer with no symptoms. Cancers of this sort should be screened for especially with family members of any sufferers.

Alternatives comment:

It starts with GPs. They should receive more training and funding to cope with suspected symptoms

239. xxxx xxxx Member of the Public

Affected Comment:

My wife died of metastatic lung cancer on xxxx August 2019. Her death was very sudden and I still do not know exactly what caused her collapse. The only symptoms she had in the two months prior to her death were a dry cough and pain in her hip. These symptoms did not improve and a subsequent x-ray and scan revealed the cancer. The cancer was diagnosed by the Oncologist on 14 August 2019 and she died before receiving any treatment 2 weeks later. The Oncologist said my wife would have had the cancer for approximately 18 months and that it was normal for symptoms to not appear until the cancer was advanced and had reached its fourth stage. My wife was 67, had never smoked and appeared to be in very good health.

Recommendation comment:

I definitely think a screening programme should be introduced. Shortly after my wife's death I suggested to our Doctor that a screening programme should be put in place, particularly as there are no symptoms during the early stages of lung cancer and that when symptoms did appear the cancer would be at a very advanced stage. I suggested an x-ray for all adults when they reached 60 years of age. I was told that this was impractical and would be too expensive.

240. xxxx xxxx Member of the Public

Affected Comment:

Yes ... x2 friends (x1 in her twenties and one in her 50s) ... neither are smokers and one a life around non-smokers

Recommendation comment:

Yes

Every life matters and ANYTHING which acts as a 'preventative measure' with regards worsening of the condition IS worthwhile ... 20s-year-old has lived a further 25 years so far (has had surgery in a number of occasions to make this possible) and has a family as a result of measures taken.

241. xxxx xxxx Member of the Public

Affected Comment:

No

Evidence Comment:

Yes, regarding a cost-effective screening method for early detection of lung cancer.

Discussion comment:

Screening needs to be considered as this will have a huge health gain for patients and will save money for the NHS.

Recommendation comment:

Yes Screening should be an important part of the overall strategy. There is an UK listed company, Cizzl Biotechnology plc, which has developed a simple and reliable blood test for an early detection of lung cancer.

This screening blood test, I believe, will help save money for the NHS and will have a huge health gain for patients.

242. [REDACTED] Member of the Public

Affected Comment:

Not directly affected

Discussion comment:

Support biomarker R&D via Cizzle Biotechnology for early detection of lung cancer.

Recommendation comment:

None

Alternatives comment:

As above

Other comments:

Grant aid Cizzle plc

243. [REDACTED] Member of the Public

Affected Comment:

My husband [REDACTED] passed away [REDACTED] /07/2020

Recommendation comment:

I think screening would be beneficial in diagnosing lung cancer early my husband would have gone for screening. It took 7 months from 1st seeing his GP to his 1st lot of treatment (which was the wrong one) if he'd had regular screening it could have been picked up early and he may have still been here.

244. [REDACTED] Member of the Public

My Mum passed away from Lung cancer January 2008 at the young age of 50.

She was for and healthy as far as we knew, walked the dog every day and enjoyed her family and friends to the full. In February 2007 she developed a thickly cough after having the flu. It carried on for a few weeks and after 3 visits to the doctors over 5 months where she was given an asthma pump, antibiotics etc she finally asked for an X-ray..... something the doctor was not keen to do but she Insisted.

Fast forward a month later and she was diagnosed with lung cancer. We were told it was terminal. This had been left undiagnosed and untreated for over 6 months. Once treatment had started it made my mum much more poorly then she had been and her health deteriorated very quickly.

I believe that with screening and better knowledge of lung cancer she would have stood a better chance at having some more precious time with us.

As her daughter who is now 41 I would like screening to be available to anyone over the age of 40. Lung cancer is the 2nd largest killer in cancer patients..... screening by needs to be available.

Recommendation comment:

Yes screening should absolutely been available for people, especially people who have lost family members to lung cancer.

245. xxxx xxxx Member of the Public

Recommendation comment:

Early identification as to whether somebody has the condition or not is vital to the long term prospects around quality of life. Present methods are invasive and expensive. Cizzle Biotech has developed a simple blood test to identify if somebody has the condition or not. Why not roll that out? It would save a considerable amount of anguish and money

246. xxxx xxxx Member of the Public

Affected Comment:

I have lost siblings to the dreadful disease.

Alternatives comment:

Look at Cizzle Biotech's early detection test in detail.

247. xxxx xxxx Member of the Public

Affected Comment:

My dad had stage 4 lung cancer diagnosed in august 2017. He passed away in November 2017. He was aged 71 a non smoker all his life, a fit and healthy man who was a black belt in karate and was a leader in the local karate club up until august 2017. When he was diagnosed he has secondary bone cancer. His only symptom was a bad shoulder which he thought was a frozen shoulder, caused by secondary bone cancer and an exacerbation of his asthma symptoms.

Evidence Comment:

Cost implication of screening possibly outweighs the care/treatment of lung cancer when finally identified

Discussion comment:

Screening and discussion around lung cancer that is separate to those considered at risk ie smokers

Recommendation comment:

Def recommended.

Alternatives comment:

Information regarding symptoms.

Especially targeted at non smokers. My father spent his last few months having to tell professionals he had never smoked!!

Other comments:

More funding in cancer research

248. xxxx xxxx Member of the Public

Affected Comment:

Friend. Took time to get definitive diagnosis in age group late 50's.

Recommendation comment:

It should be recommended for age 55+

Alternatives comment:

Better access to CXR and scanning for GP's and patients.

249. xxxx xxxx Member of the Public

Affected Comment:

If this can be screened for and lives saved then we must do it. Early screening and treatment makes better sense to all involved

Recommendation comment:

Recommend especially co

ing put of a panic when so many have missed appointments or not been able to attend appointments.

Alternatives comment:

Education and screening

250. xxxx xxxx Member of the Public

Affected Comment:

My best friend was diagnosed with lung cancer in April 2020. Following surgery and chemotherapy my friend is now in remission and continues to fight for better awareness and screening for lung cancer. If screening was available she may not have needed surgery and follow up chemo. PLEASE give full consideration to lung cancer screening. Why should there not be when it accounts for most cancer deaths in the UK.

Discussion comment:

Lung cancer screening must be considered and introduced. It could help so many people.

Recommendation comment:

Yes I do. The screening could help catch lung cancer in possibly its early stages to make survival rate much greater.

251. xxxx xxxx Member of the Public

Affected Comment:

Yes- have worked in this area with others not as a health professional and seen the damage late diagnosis does to those it affects- and their families too. If we can screen and find disease earlier then we can

prevent the rapid decline so much better. Drug therapies have improved, but late diagnosis means poor prognosis

Evidence Comment:

Coming to this late so unable to have time to review the full evidence- but the studies into lung screening have showed positive results

Discussion comment:

Please don't just target those who are most obvious- there is an increasing amount of unobvious (ie non-smoking) lung cancers which are often only detected by chance- by all means screen those who are obvious- but re-iterate with GPs and the public about reporting signs and getting a simple chest X-ray done to check for peace of mind

Recommendation comment:

It most definitely should be recommended- will take investment yes- but in time will save not only money, but resources and lives

Alternatives comment:

Blood tests? Genomic testing for different mutations?

Public awareness campaigns, GP awareness campaigns- better SOPs for nurse practitioners to follow- but we need screening now!

Other comments:

See above- please put resources into this lives depend on it

252. xxxx xxxx Member of the Public

Affected Comment:

husband died from it

Recommendation comment:

yes – and pot smokers are overlooked. there should be more research about the affects of not just tobacco but cannabis in all forms

Alternatives comment:

media – a few photos of a lung before and after may help That is what made my dad give up in the 70s.

253. xxxx xxxx Member of the Public

Affected Comment:

I was diagnosed with EGFR positive lung cancer in April 2019. As it took some time and several incorrect diagnosis, it had already spread widely to my bones and brain and I was Stage IV.

I have been on treatment for this since then, successfully, having only just had some progression in my lung and hip. Earlier diagnosis might have enabled me to have curative rather than palliative treatment.

Evidence Comment:

The evidence produced is very comprehensive but still doesn't seem to tackle the issues of, people like myself, who are diagnosed at Stage IV as they don't have any relevant history (ie a smoker) or much in the way of symptoms.

Earlier diagnosis, via a routine scan, could have prevented many of us reaching the 'point of no return' incurable and inoperable by the time we're diagnosed.

Discussion comment:

I am in favour of regular screening as is the norm with breast cancer, the cost of treatment for a patient with lung cancer, especially with new TKI drugs is considerable (around £7500 monthly) surely routine screening could save the NHS money in the long run?

Recommendation comment:

I think it should be recommended. For the reasons I gave above, treatment for some lung cancers is extremely expensive and can often be palliative only (but for many years) when routine scanning could give individuals a chance to be diagnosed early in the disease (as happens with breast cancer) allowing treatment to be curative. This treatment would then not need to be as prolonged, or necessarily as expensive, as that need for Stage IV patients.

Alternatives comment:

What alternatives?

My GP didn't even consider lung cancer when I presented with back pain, then a shadow in my lung was found.

I can't see how, other than giving GPs more time and money to see patients and fund extra tests there could have any different outcome to my diagnosis and eventual treatment?

Other comments:

Just that I fully favour routine screening.

254. xxxx xxxx Member of the Public

Affected Comment:

I am living with incurable nsc lung cancer and it has affected me and my family and as a single parent has given additional worry stress and finance worries. I am 48 and if I had the screening it may have prevented the incurable part. I may have been detected at an earlier stage and the cancer may have been curable. The impact on my children and family, sister, parents is heartbreaking to see. The cost too is high. From additional support to childrens counselling to support at school, missed lessons and education it all has a long term impact sadly and one I won't be here to see or comfort.

Evidence Comment:

The emotional side.

Discussion comment:

The age of each individual needs to be considered. Not just for over 60s. Many non smokers and women have lung cancer and this demographic needs to be considered

Recommendation comment:

I believe the screening should be recommended

To catch the cancer and mutations at an early stage. So the cancer is curable. Not incurable.

For all adults. Men and women.

These type of cancer happens so fast in some mutations. Are aggressive and grow too quick

Alternatives comment:

A programme similar to smear tests maybe an annual test or X-ray for all ages. Costly but in my opinion worth while.

Other comments:

If I can help I'd be happy too. I wish it would happen soon.

255. xxxx xxxx Member of the Public

Affected Comment:

I have lung cancer and a member of my church is receiving palliative care for lung cancer.

Evidence Comment:

It is essential that clinical trials and screening for lung cancer take place. To identify the cancer so that early treatment is possible. Early treatment will save lives and it has proven to be very effective.

Discussion comment:

Please see note above – the screening for lung cancer should be an entitlement for all.

Recommendation comment:

Please note my comment above.

Alternatives comment:

Provide financial support to the Roy Castle Lung Cancer Foundation to support all their endeavours. There are now massive demands on giving to charities with the Ukraine, Sri Lanka, fuel crisis and the cost of living rises.

Other comments:

England should have a Targeted Lung Check Programme similar to the one being introduced in Wales and Scotland.

256. xxxx xxxx Member of the Public

Affected Comment:

My husband died in November 2020 from stage 4 lung cancer which had spread to his liver and lymph nodes. He was diagnosed and was told he could only receive palliative care. He died at home five days after coming out of hospital and 11 days after the diagnosis.

Evidence Comment:

He had previously had a low dose scan of his lungs in November 2019 a year before he died and there were no abnormalities found.

Recommendation comment:

Any screening can only be a good thing if it can give people a chance of treatment before the disease has spread.

257. [REDACTED] Member of the Public

Affected Comment:

I have EGFR+ lung cancer. I have never smoked. It was diagnosed after a chest x ray, which was taken because of a chest infection, aged 48. By the time the cancer was diagnosed, it was inoperable and incurable, but it is treatable at the moment.

Recommendation comment:

If I had been screened with a chest x ray, my cancer could possibly have been picked up earlier and could possibly have been operable. So I would recommend screening with a chest x ray – if there was research to support this.

Alternatives comment:

Raise awareness of the symptoms of lung cancer such as fatigue and weight loss and back pain. Also more awareness of non-smoking lung cancer.

258. [REDACTED] Member of the Public

Affected Comment:

My son was diagnosed with ALK positive non small cell lung cancer aged 33. He was not a smoker. The cancer is caused by a rearrangement of the ALK gene. There are other types of non smoking lung cancer. Lung cancer is the biggest killer in the UK. A screening programme would save a lot of lives. It is discrimination to not offer this screening when other types of cancer do have screening programmes. As a heartbroken mother I implore you to consider lung cancer screening

Recommendation comment:

It should be recommended to save lives

Alternatives comment:

To fund research into treatments to prolong the use expectancy of patients

259. [REDACTED] Member of the Public

Affected Comment:

This has affected my 41 year old daughter, a mother of 2 small children. She was finally diagnosed with non-smokers lung cancer which had metastasised to her spatula after trying to get medical attention for 9 months. It was thought that she may have had the lung cancer for a long time which could have been picked up under a screening programme.

260. [REDACTED] Member of the Public

Affected Comment:

A very close relative passed away in 2021 due to lung cancer. They were a very fit, active and healthy 65 year old (also a never smoker) running, playing tennis and generally exercising a month before they were finally diagnosed with cancer (after initially being dismissed by a hospital for long covid & being told to 'wait it out') Early screening for this disease would have definitely saved their life.

Recommendation comment:

Yes, screening should absolutely be recommended. Too many people are dying from this awful disease when it could be easily prevented and people need a chance to receive treatment before it's too late

261. xxxx xxxx Member of the Public

Affected Comment:

My Mum died of Lung Cancer on xxxx March 2014 aged just 59. She was diagnosed with Lung Cancer just 1 month prior to her death. The only reason why she was diagnosed was because we thought she'd had a stroke, and ended up in A&E. After lots of tests, she'd found out that cancer had spread to her brain and was causing the stroke like symptoms. When lung cancer spreads to the brain, it is normally one of the last places it ends up, so knew she didn't have long. She lasted 1 month and 1 day. She left behind my dad, me (an only child) and a 15 month old grandson, who now, doesn't remember her, which breaks my heart every day. Yes my mum was a smoker, and so was high risk of getting lung cancer. If she had been routinely screened, her cancer could've been spotted at a much earlier stage. My mum was in A&E for shoulder pain a few months prior to her death, where doctors took a chest x-ray and gave her anti-biotics. They completely missed the fact my mum's lungs were riddled with cancer, because an x-ray can't distinguish between an infection and cancer. It just looks like a "cloud". My mum was never one to make a fuss, so would never complain about anything. She had tried to give up smoking several times, but nothing worked. We have screening programmes in this country for other cancers such as bowel cancer, and offer this to people who abuse their bodies by eating processed, junk food, so why can't a screening programme be offered to high risk people of lung cancer. This could've saved my mum's life, as well as many others, and by not offering this, the government are condemning people to death and have blood on their hands, from obtaining taxes from the sale of cigarettes but not offering anything to help save their lives. We don't punish women for not breast feeding, or drinking too much alcohol (linked to breast cancer) by not offering them breast screening, so why should it be any different for the number one cancer killer of women in the UK?

Recommendation comment:

It definitely should be. Lung cancer is the number one cancer killer of women in the UK. Why would we not have a screening programme for high risk patients? Screening programmes work. That's why they are live in the UK today. This has been tested with Lung Cancer and has saved lives. Why would we not want to save more lives? The whole point of the NHS is to offer a health service, not with hold a service that will inevitably lead to more deaths.

Alternatives comment:

By offering breath tests to high risk patients, which Boyle invented. By making GP's act faster when it comes to diagnosis. GP's will probably only see 1 lung cancer patient a year, (most diagnosis are made in A&E) – there needs to be more training to spot the signs earlier and not just pass it of as an infection for instance – faster tracking to CT scans, as x rays can miss the condition. So if someone is identified as high risk, they should get automatically fast tracked to a CT scan within a short time frame, and not wait for a GP to review antibiotics, chest x rays etc.

Screening will be the most effective. It will ensure high risk patients are checked. My mum could be still alive if she was part of a screening programme.

Other comments:

Something needs to be done. The government NEED to wake up to this disease. It's the NUMBER ONE killer of women in the UK! And we seem to be more worried about other cancers in women which simply isn't just or fair. Women are dying because this isn't being put into motion. MORE needs to be done and FAST. Save lives, don't ruin them.

My life has been ruined by my mum dying so suddenly. It's not just the patient that is affected, but the whole family. I've suffered with mental health, anxiety, depression, all because my Mum's cancer wasn't picked up earlier. And this will keep happening unless something CHANGES.

262. Raymund John Donnelly MBE FRCS, Member of the Public

I am writing in a personal capacity (the xxxx xxxx will send its own formal response) as a retired thoracic surgeon and as Founder and President of the xxxx xxxx, which I set up in 1990 initially as the xxxx xxxx but which we subsequently renamed after the death of xxxx xxxx. This was in recognition of his outstanding contribution to public recognition and support for our research programme into the early diagnosis of lung cancer and our campaign to highlight the issue of passive smoking which, at the time, was not well understood by the general public.

It was in 1993 that we began to fund research in the University of Liverpool into the early detection of lung cancer and for many years ploughed a lonely furrow until in the mid 2010s the major cancer charities in the UK began to invest in this area.

Using the high risk profiles developed through the Liverpool programme, research was carried out on a national basis to determine the value of radiological screening for early detection, culminating in the recently introduced pilot Targetted Lung Health Checks in selected centres across the country. These have complemented the results of other major studies in Europe and the USA that improved survival of more than 25% can be obtained through the diagnosis of earlier stage clinical lung cancer using radiological screening (CAT scans).

xxxx xxxx has played an important role in promoting the Targetted Health Checks and will be equally involved in a national lung cancer screening programme when it is introduced.

As with any cancer, early detection of lung cancer is essential to improvements in survival which still remains unacceptably low. Radiological screening will significantly improve survival statistics and must go ahead. For far too long patients with lung cancer were left behind in the public health agenda. They are now catching up and the introduction of a national lung cancer screening programme will put them on a equal footing with the other major cancers. It should not be delayed a moment longer than necessary.