UK National Screening Committee

UK National Screening Committee (UK NSC) Meeting

Evidence Map on Population Screening for Dementia

Date: 27th November 2025

Contents

Aim

This document provides background information regarding the work that has been undertaken in the triennial review of population screening for dementia in the UK.

Background

Dementia is one of the health conditions that are reviewed triennially by the UK NSC. The last evidence product we commissioned was an evidence summary that was undertaken by Solutions for Public Health in 2019, which concluded that screening for dementia should not be recommended because:

- Cognitive assessment tools were not sufficiently accurate to be used in primary care or community care settings. Optimum cut-off levels were uncertain and all cognitive assessment tools analysed in the review exhibited a wide range of sensitivity and specificity scores.

- The positive predictive value of cognitive assessment tools in people under 85 was particularly poor. This meant that the majority of people with a positive screening test result would be found not to have dementia on further evaluation.

- Mild cognitive impairment (MCI) represents a potential early symptomatic stage of dementia. However, the review found that there was insufficient information on the epidemiology and

natural history of MCI and its clinical progression, particularly with regard to its relationship with dementia.

- The available evidence on the effectiveness of pharmacological and non-pharmacological interventions for people with MCI or dementia was often inconsistent or inconclusive. When statistically significant, the effects seen were small and their clinical significance remained to be ascertained.

- Evidence from US studies suggested that the uptake of further diagnostic testing among those with a positive screening result was low, and it was not clear whether this would also be the case within a UK context.

Current UK NSC Recommendation

Currently, population screening for dementia is not recommended based on conclusions drawn from the 2019 evidence summary.

Evidence Map

The UK NSC evidence team commissioned a review of the volume and type of evidence available on population screening for dementia in June 2024 as part of the 3-year cyclical review of evidence available on the condition. The evidence map was conducted by the NIHR Evidence Synthesis Group (EnSygnN) based at the Sheffield Centre for Health and Related Research (ScHARR), University of Sheffield. The following three questions were addressed to capture evidence that had been published since the last review:

1. What is the volume and type of evidence available on the accuracy of screening tests used to detect MCI and/or any type of dementia?

2. What is the volume and type of evidence available on the pharmacological and non-pharmacological interventions used to treat asymptomatic or pre-symptomatic adults with MCI and/or any type of dementia identified through screening?

3. What is the available evidence of active/on-going clinical trials, observational studies or systematic reviews investigating innovations in screening and/or diagnostic tests for MCI and/or any type of dementia, including new proposed medical interventions?

Summary of Findings

Question 1:

A systematic search of the literature yielded 45 studies on screening tests for dementia and/or MCI, of which 19 were systematic reviews, 14 diagnostic cohort studies and 12 diagnostic case-control studies.

In summary, new and updated systematic reviews continue to point to a lack of evidence to support population screening for MCI and dementia and a randomised controlled trial in the USA

reported no benefit from screening. Although there is a substantial volume of new evidence and that an evidence map does not include formal quality assessment, the type of evidence identified is unlikely to lead to a change in the UK NSC's current recommendation.

Question 2:

A total of 51 studies related to treatment interventions were found. Evidence on asymptomatic or pre-symptomatic adults was limited (6 studies) so studies on other early symptomatic/non-screened populations (including people diagnosed with MCI or 'prodromal Alzheimer's disease (AD)') were considered for inclusion as specified in the protocol. No studies of people with screen-detected MCI associated with population screening programmes were identified.

The volume of potentially relevant new evidence is large but pharmacological interventions evaluated in randomised trials have yet to demonstrate meaningful benefits for people with preclinical or early symptomatic dementia, especially when safety concerns and associated costs are taken into account. There are large numbers of new systematic reviews and trials of non-pharmacological interventions for people with MCI but many of these are complex and/or experimental and links with population screening are lacking.

Question 3:

Horizon scanning identified evidence of 18 active research or development initiative reports. These included 11 on-going clinical trials, 6 published study protocols, and 1 expert review.

Conclusions

Whilst there is a substantial volume of new evidence and that an evidence map does not include formal quality assessment; the findings of this evidence map appear unlikely to impact the current recommendation not to screen for dementia.

Recommendations

On the basis of this evidence map, the volume and type of evidence related to screening for dementia appears insufficient to justify commissioning an evidence summary at this stage. A recommendation was made to re-consider this topic in 3-years' time.

Public Consultation

A 3-month public consultation was hosted on the UK NSC GOV.UK website from 17th June to 9th September 2025. The UK NSC consulted on the findings of the evidence map and the recommendation not to screen for dementia in the UK. Direct emails were sent out to 12 stakeholders (*please see Annex A)*. A total number of 16 consultation responses were received *(please see Annex B for full comments)* from a wide range of professionals, lay members of the public and stakeholder organisations which included:

- Consultant Old Age Psychiatrists x 2

- Members of the public x 7
- Consultant Geriatricians x 3
- General Practitioners x 4
- Royal College of General Practitioners
- British Geriatrics Society
- Association of British Neurologists
- University of Cambridge
- Alzheimer's Society
- Alzheimer's Research UK
- Down's Syndrome Association
- Dementia UK
- Dementia Centre of Excellence
- Dementia Industry Group

The key points raised by stakeholders are summarised below:

I. There was a general agreement with the findings of the evidence map and the recommendation not to introduce population screening for dementia in the UK.

- Representatives of key stakeholders such as Alzheimer's Society, Alzheimer's Research UK, British Geriatrics Society, Dementia UK and Dementia Industry Group fully endorsed the recommendation not to screen for dementia in the UK.

II. There was partial agreement on the recommendation to re-consider the topic according to the UK NSC review cycle, when the evidence base on protein biomarker tests and disease modifying treatments had matured.

- Representatives from Alzheimer's Society, Alzheimer's UK and Dementia UK requested the UK NSC to continue monitoring the evidence base and to conduct an annual light touch review instead of waiting for 3 years to elapse.

- Representatives from Dementia Industry Group (DIG), a life sciences industry collaboration group, asserted that "innovation in dementia care and treatment has transformative potential and we are on the precipice of realising significant, positive changes in the way in which the

disease is diagnosed and managed," in regard to the recommendation to review the topic in 3 years.

Response: We are monitoring new developments in the field as part of the horizon scanning function of the UK NSC. Stakeholders are also invited to bring significant developments in the evidence base to the Committee's attention as part of the open call for topics.

III. There were calls for targeted screening for dementia to be considered according to dementia-type, high-risk population group and healthcare setting:

- Representatives from Dementia UK requested for rarer types of dementia to be reviewed separately.
- A consultant old age psychiatrist suggested targeted screening in acute and rehabilitation settings for elderly people.
- Another consultant geriatrician suggested targeted screening for people aged over 65yrs.
- Organisations that advocate for people with learning disabilities such as the Down's Syndrome Association, Association of British Neurologists, Down Syndrome Medical Interest Group and Dementia UK raised concerns about the omission of a specialist focus on this patient group.
    - Representatives from Down's Syndrome Association requested the UK NSC to consider a differentiated approach to screening people with Down's syndrome because adults with this condition are more likely to develop dementia at an earlier age than the general population. Furthermore, dementia was reported to be the underlying cause of death in more than 70% of adults with Down's syndrome aged over 35yrs (Hithersay et al., 2018). *"The early signs of dementia are often ignored and put down to the individual having Down's syndrome"* and therefore underdiagnosed. The standard assessment tool utilised in primary care is the Mini-Mental State Examination (MMSE) which is inaccessible and inappropriate for people with a learning disability.

Response: The scope of the current evidence map was limited to population-based screening in a community setting for people who have not presented to their GP with symptoms of dementia. The recommendations in this review do not extend to the assessment of particular clinical groups. If suggesting targeted screening for people with learning disabilities or any other clinical group, we would encourage submitting a screening programme proposal through the UK NSC open call for topics.

ARG members reviewed and provided sign-off on the evidence map and all public consultation comments that were received, including the responses made by the UK NSC secretariat.

UK NSC Recommendation Request

The UK NSC is requested to approve the recommendation that based on the evidence provided a population screening programme for dementia should not be introduced.

Annex A: List of Organisations Contacted

1. Alzheimer's Research UK
2. Alzheimer's Society
3. Association of British Neurologists
4. British Geriatrics Society
5. Down Syndrome Medical Interest Group
6. Royal College of General Practitioners
7. Royal College of Nursing
8. Royal College of Physicians
9. Royal College of Physicians and Surgeons of Glasgow
10. Royal College of Physicians of Edinburgh
11. Royal College of Psychiatrists
12. The British Psychological Society

Annex B: Consultation Responses

1. XXX XXX, Consultant Old Age Psychiatry, XXX NHS Trust

Condition: Dementia

At present there are no valid and specific primary care screening tools to provide sound clinical and economic (planning for services and cost benefit analysis) reason to recommend population wide screening for dementia.

By recommending screening, we would be burdening existing services which are already overwhelmed by managing several co-morbid long term health conditions in the frail elderly.

Targeted screening in acute and rehab settings for elderly would have some tangible benefit.

2. XXX XXX, Member of the Public

Affected Comment:

My next door neighbour has been diagnosed with dementia and in the last 12 months we have noticed a rapid decline sadly. He is 78 and is supposed to be enjoying his retirement but his children and wife are having to readjust their lives to be with him, to ensure he wakes up and washes himself, to encourage him to walk and get outside and take part in social activities. I have been super shocked how quickly he has forgotten who i am, given we have been neighbours for 30yrs.

Discussion comment:

I feel sad that the NSC will not commission work on this for another 3 years- when the stats show the increased incidence of dementia amongst our older population. If we are improve mortality and reach the same life expectancy as our Nordic and Far East Countries we need to catch diseases earlier.

Recommendation comment:

I think it should be recommended after a robust pilot has been undertaken over the next 3 years if the data proves conclusive this would be a life changer.

Alternatives comment:

- stop elderley people living in isolation
- ensure communities are able to look after their old
- join up health and social care
- take a look at models in the south asian community
- ensure HCPs are well trained to look after those with dementia and ensure carers have the personalised support that they need

3. XXX XXX, Consultant Geriatrician & Associate Medical Director Dementia and Delirium, Department of Older Persons Medicine, University Hospitals of XXX

I wished to respond to the proposal to not to instigate population wide screening for dementia, unfortunately I was unable to download the response form so hope this will suffice.

From the report the evidence and rationale for whole population screening is limited and this is clearly set out within the guidance, in addition to the limitations of testing for early diagnosis and current treatment options. I would suggest, however, that there remains a benefit to screening those adults over 65 presenting to medical and community services and in those who have had an episode of delirium. This would be in line with the GIRFT and British Geriatric Society guidance and recommendations. Routine cognitive screening should be part of a comprehensive geriatric assessment for all older adults, and should remain so, and GIRFT right care dementia scenario reflects the impact of an earlier diagnosis for this group of patients. Early diagnosis of dementia in older adults allows for consideration of treatment therapies, increased support in the community, future care preferences to be discussed and a reduced impact on NHS and social services. Nearly a third of people living with dementia never receive a formal diagnosis and post diagnostic support is often unavailable until there is a crisis. Early diagnosis in this group of older adults would be of huge population benefit. It is recognised that an increase in screening would require additional funding to memory service providers and mental and community health services.

CQUINS were previously attached to undertaking cognitive screens on admission to hospital and this would be welcomed again to encourage completion and reduce the impact of those admitted to acute services due to a crisis in their cognitive function. In addition, it is well known that those with an episode of delirium are at higher risk of developing dementia and those with dementia are at a higher risk of delirium. Delirium has a huge impact on acute NHS services and negative outcomes for patients. Screening following an episode of delirium allows for identification of dementia and strategies to prevent further delirium episodes.

In summary whilst whole population screening for early dementia in under 65's may not have the intended benefit, it would potentially be of benefit to ensure screening, using recognised cognitive assessment tools, for over 65's.

UK National Screening Committee

4. XXX XXX, UCL/NHS

Name:	XXX XXX	**Email address:**	xxxxx
Organisation (if appropriate):	UCL/ NHS		
Role:	**Clinical Academic/ GP**		

Do you consent to your name being published on the UK NSC website alongside your response?

Section and / or page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
Section 4.1 Implications, p10	Jiahui Jin, Benjamin Junting Li, Yin Leng Theng, Why people hesitate about dementia screening: A systematic review and meta-analysis, Social Science & Medicine, Volume 382, 2025, 118360, ISSN 0277-9536, https://doi.org/10.1016/j.socscimed.2025.118360. (https://www.sciencedirect.com/science/article/pii/S0277953625006914)	"Psychological barriers, such as fear of diagnosis, stigma, and emotional distress, significantly contribute to screening hesitancy. Successful strategies should foster supportive environments that acknowledge these concerns while offering hope and coping strategies." (p10, Jin et al) This paper highlights some of the facilitators and barriers to screening. Fear and stigma of the diagnosis is a major barrier. It is important to create a supportive environment for those who are diagnosed, otherwise this could contribute to screening hesitancy.

5. XXX XXX, Down's Syndrome Association

Dear DHSC colleagues

Please find attached a response from the Down's Syndrome Association in respect of the current consultation on evidence relating to general population dementia screening.

Kind regards

XXX XXX

About the DSA

The Down's Syndrome Association is a national charity focusing on all aspects of living successfully with Down's syndrome. Established in 1970, we have members throughout England, Wales and Northern Ireland. The Association is in contact with over 100 affiliated local support groups and a range of professionals from different agencies. The aim of the organisation is to help people who have Down's syndrome lead full and rewarding lives.

We are the lead provider of information, advocacy, support and training to anyone with an interest in Down's syndrome. We are a membership-led organisation, with our membership comprising primarily the family-carers of children and adults who have Down's syndrome and a growing membership of adults with Down's syndrome aged 18+. We are well placed to reflect the needs and views of people we seek to serve.

We have a commitment to inclusive participation and work closely with a diverse group of individuals who have Down's syndrome called "Our Voice", who come together regularly to help shape and inform our work.

About Down's syndrome

Down's syndrome is a genetic condition, caused by the presence of an extra chromosome 21 in the body's cells. Everyone with the condition will have some degree of learning disability. In addition, there are several associated medical conditions, which affect some, but not all, people who have Down's syndrome, meaning the services that they access from the NHS (and social care settings) are of paramount importance to their wellbeing.

The number of people in England and Wales with the condition was estimated as 37,090[1] in 2013.

The Down's Syndrome Association provides lifelong support, in the form of information and advice for people who have Down's syndrome and their parents and carers.

Some people who have Down's syndrome lead semi-independent lives in a supported environment and others, with more complex needs, will always require a high level of support. Generally, needs increase with age.

With appropriate healthcare, many people who have Down's syndrome are now living to the age of 60 and beyond.

Although evidence to support the introduction of generic dementia screening for the whole adult population may be inconclusive, we feel that adults who have Down's syndrome are a patient group that requires a differentiated approach, based on strong and enduring evidence to illustrate that they are a population at greater risk of developing dementia.

Why is the issue of dementia important for adults who have Down's syndrome?

Adults who have Down's syndrome are far more likely to develop dementia and the onset of dementia begins at a much younger age than in the general population. Strategies that promote healthy ageing and heightened awareness are therefore important.

[1] Wu J, Morris JK The population prevalence of Down's syndrome in England and Wales in 2011 Eur J Hum Genet 2013 Sep; 21(9):1016-9. doi: 10.1038/ejhg.2012.294. Epub 2013

Incidence

Incidence rises from 9% of adults with Down's syndrome aged 40-49 years to 32% of adults aged 50-59 years (Coppus et al, 2006). Dementia is an underlying cause of death in more than 70% of adults with Down syndrome aged over 35 years (Hithersay et al 2018). McCarron et al (2014) report a cumulative incidence of dementia of 90% by the age of 65 years.

Changing demographics

We celebrate that mean life expectancy for people who have Down's syndrome increased from less than 10 years in early 1900s to a median of 58 by 2011. (Wu et al, 2011)

This means that, over the last 30 or so years, public services have seen a huge rise in the numbers of people who have Down's syndrome who are aged in their 50s, 60s and 70s. Many service providers need help in understanding how to respond to these changing needs.

Diagnostic Overshadowing

The early signs of dementia are often ignored and are put down to an "individual having Down's syndrome ". This means that some people present very late for a diagnosis.

Conversely, assumptions are sometimes made, meaning that *any* change is assumed to be dementia when it something else that would be treatable via a different type of intervention.

There is therefore a need for a differentiated diagnosis, which correctly identifies and suggest interventions for other causes of decline in middle to older age. This would include:

1. Life stresses, especially bereavement
2. Depression
3. Changing sensory impairments
4. Confusion brought about by an infection
5. Untreated thyroid condition

6. Menopause in women
7. Musculoskeletal issues and changes in mobility due to issues with joints
8. Side-effects or interactions between other prescribed medications, which may need review
9. Non-dementia related regression (which can be temporary and treatable if cause is understood)

Lack of baseline assessments

The British Psychological Society has issued guidance on baseline assessments in their Division of Clinical Psychology, faculty for People with Intellectual Disabilities publication “Dementia and People with Intellectual Disabilities Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia” April 2015.

Despite British Psychological Society good practice guidance and an improving picture across the country, many adults who have Down’s syndrome do not receive an appropriate baseline assessment for dementia.

The BPS recommend services set up register of adults who have Down’s syndrome, conduct baseline assessments of cognitive and adaptive functioning by age 30.

Frequency of prospective monitoring for dementia should be matched to rising risk with age. Monitoring should be every two years for those in their 40s; and annually for those 50+.

Use of an appropriate assessment tool

We are aware that the usual assessment tool utilised in primary care is the Mini-Mental State Examination (MMSE). This is inaccessible for most people who have a learning disability and should not be used as a cognitive assessment tool for them. However, calls to our helpline tell us that is frequently employed. This is a waste of clinicians’ time and causes distress to the individual subjected to this wholly inappropriate assessment method and can lead to a reluctance to engage and should clearly be avoided. This highlights a need for general awareness training for primary care staff, something that the Down’s Syndrome Association is very keen to facilitate (and has been doing at an ICB level across England for some years).

There are numerous cognitive assessment tools that are accessible for people who have a learning disability and 3 of the most regularly used ones are:

CAMDEX CAMDEX-DS-II: A Comprehensive Assessment for Dementia in People with Down Syndrome and Others with Intellectual Disabilities (2nd edition) – Manual - Pavilion Publishing (pavpub.com)

DSQIID www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/dementia-screening-questionnaire-for-individuals-with-intellectual-disabilities/31FD5C49F5F9A08827F16AC4D6B775FE

DLD www.pearsonclinical.co.uk/store/ukassessments/en/Store/Professional-Assessments/Cognition-%26-Neuro/Dementia-Questionnaire-for-People-with-Learning-Disabilities/p/P100009213.html?srsltid=AfmBOorBgUl9FnyIeK72RqpTxiYhd3b7m8xy5hOU0UEt49AwWejwS-TQ

Limitations of Learning Disability Annual Health Checks

Since 2008, individuals known to their GP as having a learning disability are entitled to an Annual Health Check. These are variable in quality and although the check should touch upon cognitive function and any concerns about a decline are insufficiently detailed to constitute a proper dementia assessment. The likelihood that GPs and practice nurses have sufficient awareness of the need for a differentiated (accessible assessment tool, see above) also means that the Annual Health Check is unlikely to reliably identify those individuals who may be developing dementia

Access to medications

There are currently a very limited range of medications licenced for use in the treatment of Alzheimer's disease e.g. Donepezil. The medication can slow the progression of the decline rather than reverse the effects of the dementia. Where clinically indicated, adults who have Down's syndrome who develop Alzheimer's type dementia should be given the same access to these drugs as someone who does not have Down's syndrome. There seems to a reluctance to try these medications amongst the population of people who have Down's syndrome, as many clinicians seem to think they will be ineffective.

There are also a range of new medications in development that are demonstrating very exciting benefits. It is of paramount importance that individuals who have Down's syndrome are included as participants in drug trials in the UK and that, given the greater likelihood of developing dementia, they are prioritised for early access to these medications as soon as they become available.

Historically, people who have Down's syndrome have played a very important part in research relating to medications for dementia and greatly helped our understanding of the aetiology of the condition. It is therefore essential that the altruism of this population of citizens is recognised by affording people who have Down's syndrome swift access to new drug interventions that may be available soon.

We would draw attention to the ground-breaking work being undertaken at UK based universities undertaking research into Down's syndrome and dementia e.g. Defeating Dementia www.cam.ac.uk/defeating-dementia-in-down's-syndrome and LonDownS Consortium www.ucl.ac.uk/london-down-syndrome-consortium.

This research suggests that new interventions may become possible or it could lead to a greater level of understanding into the specific risk factors for people who have Down's syndrome. This area of research should be given adequate levels of funding to ensure the researchers are able to fulfil their aims of improving outcomes for people who have Down's syndrome and develop dementia.

Resources

The Down's Syndrome Association has produced a range of resources that focus on ageing and Dementia. These include:

Getting Older Booklet Ageing-Final-Format-5th-April-DSMIG.pdf (downs-syndrome.org.uk)

Down's syndrome and Alzheimer's disease 2018.09.Alzheimers-Disease_DSMIG.pdf (downs-syndrome.org.uk)

A range of our other health series booklets e.g. thyroid, depression, vision and hearing etc. Health and Wellbeing - Downs Syndrome Association (downs-syndrome.org.uk)

In January 2025 we released a comprehensive new resource to underpin all our dementia work – keeping people who have Down's syndrome well before and during dementia Workbook for families and staff. Keeping people who have Down's syndrome well before and during dementia - hard copy - Downs Syndrome Association

This 200-page resource contains a wealth of information and is designed to be personalised to individuals who have Down's syndrome. It starts by raising awareness of what changes to look for in a person who may be developing dementia, and it can be used as an ongoing record and resource within an individual's personal health record. The Workbook is particularly relevant to adults who are living in supported living settings, who may have a team of support staff assisting them. Care staff are often quite a transient workforce and do not always have a long-term knowledge of the individual they support – this can mean that subtle changes in a person's level of functioning, memory and skills go unnoticed.

Since its launch, the feedback for the Workbook has been extremely positive – one leading dementia professional told us:

This is a brilliant resource. It is an excellent way to introduce Dementia to new and established staff, hopefully taking away some of the fear and stigma associated with this disease, and offering suggestions and ideas, especially failure free activities.

Family members have also described how valuable it has been:

We have a son with Down's syndrome who will shortly be 50 years old. This book will be very useful to us on our journey. We particularly like the broadness of approach which the manual takes.

I like all the recording templates that are in the folder which are very useful for the care provider to monitor. It's easy to understand the different stage and what to look out for.

In June of this year, the publication won the Training and Workforce Development category in the UK Dementia Care Awards 2025

Training

The DSA regularly provides training for anyone who has an interest in Down's syndrome, ageing and dementia. This used to be a full day in person session. We have now moved this to be an online session and can provide either a 90-minute introductory session or a half-day bespoke session: Down's syndrome, ageing and dementia - Downs Syndrome Association (downs-syndrome.org.uk)

Additional Research focused on dementia with Down's Syndrome Association involvement

We are currently involved with a number of studies focused around ageing.

One of the most exciting is the Abate Study, which is a revolutionary trial of a new generation of possible treatments The ABATE study [The ABATE study - Downs Syndrome Association]

There is also a study that focuses on new and innovative ways of detecting dementia The REVEAL Study [The REVEAL Study - Downs Syndrome Association]

We also regularly engage with the leading dementia researcher, Professor John Hardy and would suggest that he has some very important insights to share on how the population of people who have Down's syndrome need to be considered in relation to dementia treatments [John Hardy | UK Dementia Research Institute at UCL - UCL – University College London]

References

Coppus, A., Evenhuis, H., Verberne, G. J., Visser, F., Van Gool, P., Eikelenboom, P., et al. (2006). Dementia and mortality in persons with Down's syndrome. Journal of Intellectual Disability Research, 50(Pt 10), 768-777

A prospective 14-year longitudinal follow-up of dementia in persons with Down syndrome M. McCarron, P. McCallion, E. Reilly & N. Mulryan. Journal of Intellectual Disability Research volume 58 part 1 pp 61–70 January 2014

6. XXX XXX, ICB, Royal College of General Practitioners

Name:	XXX XXX	**Email address:**	XXX XXX
Organisation (if appropriate):	RCGP		
Role:	**Special interest group for learning disability**		
Do you consent to your name being published on the UK NSC website alongside your response? no			

Section and / or page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
Page 5	No mention of the differences and difficulties of **screening** in people with a learning disability	There should be mention of the difficulties in recognition, assessment, diagnostics and management for people with a learning disability, and people with Downs syndrome, see enclosed document  Dementia population screening (002).docx from the Downs syndrome association People with a learning disability experience intersectional health inequality of access, delivery and experience of care, and their memory concerns can be overlooked such as in diagnostic overshadowing. Professional curiosity about the possibility of a learning disability should also be inherent in any guidance, and that mental capacity act consideration is given.

		We know that minoritised ethnic communities experience worse care, and it is important for any promotional materials, information or assessment tools are routinely translated, and should routinely be available in easy read. People with a learning disability and their carers are not always able to notice if a dementia syndrome is coming on, the assessment tools are different and they need more of a baseline and functional assessments and the diagnostics may need significant reasonable adjustments e.g., for scanning or verbal/written assessments. We would advocate for consideration of a different approach, and a more structured approach e.g., starting to screen at an age where people with a learning disability may experience dementia e.g., around age 50, using an adjusted assessment tool, such as the DSQID, and having reasonable adjustments as the standard for any diagnostics.

UK National Screening Committee

7. XXX XXX, British Geriatrics Society

Name:	XXX XXX	**Email address:**	xxxxx
Organisation (if appropriate):	British Geriatrics Society		
Role:	**Dementia, Delirium and Brain Health special interest group – trainee representative & delirium representative**		
Do you consent to your name being published on the UK NSC website alongside your response? Yes			

Section and / or page number	Text or issue to which comments relate	Comment *Please use a new row for each comment and add extra rows as required.*
	Search strategy	The search strategy is comprehensive and identifies a broad range of evidence to support the conclusions of the report.
	Question 1	We agree that there is insufficient evidence to support implementation of population screening for dementia. As provided in the evidence summary, while there are many approaches which could be taken to implement a screening programme, there is limited evidence of benefit following screening. Additionally, the implications of a positive test result do not justify population screening – i.e. a lack of treatments to prevent or reverse progression of cognitive impairment. Nevertheless, we believe that there should be a comment which acknowledges that there are tests available which have got good sensitivity and specificity for dementia screening, as this is not made clear in the text. There may have been other reasons why these tests were not considered to be appropriate (e.g. inconclusive cut-off scores or PPVs as was the case in the 2018 report) – if this was the case then suggest mentioning this.
	Question 2	As noted above, at present there is insufficient evidence of effective treatment to support implementation of a national screening programme.

	Question 3	On the basis of the evidence presented in the report, we agree that population screening is not currently supported.
	Overall	The evidence synthesis appears balanced and robust. At present we support the conclusion of the report that population screening for dementia is not indicated. We note that significant work is underway to develop disease-modifying treatment and to establish accurate multi-modal diagnostic tools, meaning this recommendation may well change in the future.

8. XXX XXX, Dementia Centre of Excellence

I am writing to provide expert input regarding dementia risk screening (Q3), drawing on extensive systematic reviews my team has undertaken in this rapidly evolving field. Specifically, I would like to see more of a discussion around dementia risk prediction as part of the screening committee's considerations. This discussion could be supported by the extensive body of work my team has undertaken in this field.

Current State of Evidence

My team has conducted comprehensive reviews examining dementia risk prediction modelling (Brain et al., 2024[1]; Tang et al., 2015[2] and Stephan et al., 2010[3]; citations below) and population attributable fractions of modifiable risk factors (Stephan et al., 2024[4]). While this work demonstrates significant advances in our understanding of dementia risk factors and prediction capabilities, important limitations remain regarding model accuracy and validation for population screening applications. I would be keen to see this evidence integrated into the recommendation.

Key Findings and Limitations

My systematic reviews reveal that although substantial progress has been made in identifying modifiable risk factors[1-3], with our meta-analysis showing a considerable proportion of dementia cases potentially involve modifiable factors[4], the prediction models currently available lack the accuracy and robust validation necessary for clinical/population-level implementation.

Current Recommendation

Based on the most comprehensive review of the evidence to date, would it be possible to highlight that dementia risk screening (in addition to case finding) would not be recommended at this time. While the potential for prevention-focused screening is promising, we believe that accurate and well-validated prediction models must be developed and rigorously tested before such screening can be responsibly implemented at a population level.

Citations

Brain J, Kafadar AH, Errington L, et al. What's New in Dementia Risk Prediction Modelling? An Updated Systematic Review. Dement Geriatr Cogn Dis Extra. Jan-Dec 2024;14(1):49-74. doi:10.1159/000539744

Tang EY, Harrison SL, Errington L, et al. Current Developments in Dementia Risk Prediction Modelling: An Updated Systematic Review. PLoS One. 2015;10(9):e0136181. doi:10.1371/journal.pone.0136181

Stephan BC, Kurth T, Matthews FE, Brayne C, Dufouil C. Dementia risk prediction in the population: are screening models accurate? Nat Rev Neurol. Jun 2010;6(6):318-26. doi:10.1038/nrneurol.2010.54

Stephan BCM, Cochrane L, Kafadar AH, et al. Population attributable fractions of modifiable risk factors for dementia: a systematic review and meta-analysis. Lancet Healthy Longev. Jun 2024;5(6):e406-e421. doi:10.1016/s2666-7568(24)00061-8

9. XXX XXX, GP

As a previous GP lead for dementia in my area (2010-2016), I have thought about dementia screening, diagnosis and management a lot. As a practising GP, I continue to look after people who have concerns about their memory, and those who have been diagnosed with dementia.

As I have gained experience, I have used screening tools less and less. If someone tells me about minor memory problems then I may use them, in anticipation of good results and to help reassure the patient that the issue is unlikely to be clinically serious. If the patient tells me about serious memory/cognitive lapses then I need to investigate, irrespective of the tool. If I end up referring to memory clinic, then I know they will do the ACE-R, which I do not have time to do in a GP appointment!

Some people do not want to be diagnosed with dementia; they see it as stigmatising. Some people are keen for referral and diagnosis, as they anticipate there is something meaningful that we can do. By asking screening questions we tend to raise this hope. Some people do benefit from the diagnosis in the sense that it can sometimes help smooth the way into getting support from social services (but then they are shocked because many do not realise such support is means-tested).

I have been unimpressed by the available medications for dementia, especially when I have to manage the side-effects. The single most useful thing I have found is the Mental Health of Older Adults team offering support to families and carers around the Behavioural and Psychological Symptoms in Dementia.

Overall, I support the NSC recommendation that we should NOT screen for dementia.

What we SHOULD be doing is discussing with people about advanced care plans. Have they made a will? Considered Power of Attorney? Care at end of life? This is good practice. But we should be doing this with all older people and those with long term conditions, not only those with possible or diagnosed dementia.

10. XXX XXX, Dementia UK

Dementia UK consultation response to the UK National Screening Committee recommendation on dementia screening:

1. Introduction

1.1. Dementia UK welcomes the opportunity to respond to the UK National Screening Committee's (NSC) consultation on the recommendation not to introduce a screening programme for dementia at this time.

1.2. We recognise the complexity of implementing a screening programme for dementia, and we understand the NSC's concerns regarding the current limitations of screening tools and available disease-modifying treatments.

1.3. However, we urge the Committee to maintain a flexible position that keeps the decision under active review, in light of the rapid pace of innovation in both pharmacological and non-pharmacological interventions. Dementia UK urges that, due to the current speed of innovation, there is a minimum of a light-touch review every year.

1.4. We also urge that the benefits of screening for rarer types of dementia are reviewed in separation from more common forms, as well as groups who are at higher risk of dementia and may need targeted interventions (such as individuals with learning disabilities).

1.5. Most importantly, we emphasise that screening for dementia is not solely about medical treatment; it is also about enabling timely access to critical post-diagnostic support for individuals and their families. The quality and timeliness of family support can have a significant and lasting impact on a range of outcomes, including hospital admissions and personalisation of care.

2. Recommendations

2.1.Dementia UK recommends that the UK NSC:

• Keep the decision not to screen for dementia under active review, with explicit timelines and criteria for reconsideration in light of new evidence. Due to the current speed of innovation we urge a light-touch review of the decision on an annual basis.

• Consider targeted screening for rarer dementias and for high-risk groups immediately, drawing on the risk-stratified models used for other conditions.

• Acknowledge and value psycho-social interventions as valid outcomes of screening, not just pharmacological treatments.

• Begin system preparedness planning now, to ensure rapid adoption of emerging screening technologies, diagnostics and therapies.

• Integrate dementia screening planning into wider planning regarding changes to the broader health and social care system.

• Embed post-diagnostic family support as a non-negotiable element of any screening approach.

3. About Dementia UK

3.1. Dementia UK is the specialist dementia nurse charity. Our dementia specialist nurses, called Admiral Nurses, whom we continually support and develop, provide life-changing care and support for families affected by all forms of dementia. Admiral Nurses help families and carers manage complex needs by providing clinical support, care co-ordination and advocacy on behalf of people with dementia and their families.

3.2. Clinical support from Admiral Nurses spans pre-diagnosis through post-diagnostic care, through pathway transitions, to end-of-life care and post-bereavement support. Their specialist support can help people living with dementia stay independent for longer, and ensure families are better supported in their caring role. This also puts pressure on the NHS and social care services and provides cost savings by reducing crises and the avoidable use of acute hospital services. Admiral Nurses also provide health and social care services with specialist advice and best practice guidance. For more information, visit www.dementiauk.org

4. Preparing for new screening and treatment technologies

4.1. As noted within the committee papers, several promising technologies are being developed to screen for, diagnose and treat dementia.

4.2. A blood test for dementia diagnosis has already been approved for use by the Food and Drug Administration (FDA) in the United States, and pilots for blood tests are taking place in Europe, including some parts of Scotland.

The Blood Biomarker Challenge – a multi-million pound programme supported by a coalition of dementia research organisations – will pilot the implementation of new blood tests in the NHS that can help to diagnose different forms of dementia earlier, more accessibly, and potentially more efficiently than current methods.[i]

4.3. Likewise, although NICE (National Institute of Health and Care Excellence) has recently rejected disease-modifying treatments for Alzheimer's disease based on a lack of cost-effectiveness[ii], NSC's documents acknowledge that new pharmacological and non-pharmacological interventions are in development. 29 more treatments in late-stage trials could be available by 2030, and more than 180 trials worldwide are

testing nearly 140 experimental treatments for Alzheimer's disease alone.[iii] It is therefore essential to avoid designing a screening policy that is reactive and slow to adapt; instead, we must be proactive in preparing the system for integration of these innovations.

4.4. Given this, Dementia UK urges that a flexible approach to screening recommendations for dementia is taken, with the decision being revisited in the event of NICE or SMC (Scottish Medicines Consortium) approval of disease-modifying treatments or biomarker tests. Dementia UK recommends that the National Screening Committee keep the decision not to screen dementia under active review, with explicit timelines and criteria for reconsideration in light of new evidence, with an annual light-touch review of the decision to keep pace with innovation.

4.5. Emerging pharmacological treatments and biomarkers will also necessitate a significant shift in the NHS's approach to dementia diagnosis and care. We recommend that the NSC, working with the Department of Health and Social Care, begin planning now for:

• **Workforce and infrastructure capacity**: Specialist dementia nurses and primary care clinicians must be trained to deliver both screening, treatments and post-diagnostic support. Likewise, pre- and post-diagnostic services should be prepared for a possible increase in referrals.

• **Care coordination**: Screening must trigger a clearly defined pathway into specialist services and community-based support.

• **Infrastructure for genomic testing:** In alignment with the NHS Long Term Plan's commitment to expanding genomics, health services must be equipped to handle genomic testing if a strategy for this is developed.[iv]

4.6. Without such preparation, the benefits of new screening tools and treatments will be severely constrained, and families will continue to face long waits and fragmented care following diagnosis.

5. Integration with broader NHS strategies

5.1. There may also be widespread changes and innovations that could impact the feasibility and effectiveness of dementia screening, due to changes to the health and social care landscape. Dementia UK urges that future reviews of dementia screening align with wider NHS initiatives, in light of the recent publication of the NHS 10-year plan and future development of the Modern Services Framework for frailty and dementia.

5.2. The NHS 10-year plan includes commitments to early diagnosis and expanding genomics-based prevention. Dementia is explicitly named as a condition which will have targeted preventative strategies prioritised, alongside cardiovascular disease, frailty, and mental health. Specific commitments include:

• Using AI to implement genomics and predictive analysis to ascertain the likelihood of a person developing a condition before it occurs, support early detection of disease, and enable personalised prevention and treatment. Genomic insights will initially be used for cardiovascular disease and then may have wider roll-out to other conditions, including dementia, subject to evaluation.

• The NHS App will provide alerts to participate in risk-stratified screening and other diagnostic tests.

• There will be implementation and adoption of using AI for screening pathways.

5.3. Dementia UK would welcome the opportunity to input into, or discuss, how dementia screening may align with likely changes to health and social care systems.

6. Stratified screening for rare dementias and groups at higher risk of dementia

6.1. The Committee's consultation combines evidence regarding different forms of dementia. While dementias share commonalities, Dementia UK urges that different dementias and groups more at risk or facing greater inequalities are considered separately when deciding whether or not to screen, as testing can vary significantly.

6.2. For example, several rare dementias can be screened for using genetic testing, which has a high degree of predictive value. A prime example is frontotemporal dementia (FTD). In individuals with a strong family history, genetic testing can identify carriers of pathogenic variants with high specificity and sensitivity. Specifically targeting the three most common mutations involving TDP-43, MAPT, and PGRN genes demonstrates promising predictive ability, which means they could indeed assist in early identification of FTD risk.[v] Familial/autosomal dominant Alzheimer's[vi] and prion diseases[vii] can also have genetic testing. Unlike the broader population, these high-risk groups can be offered meaningful screening and monitoring today.

6.3. We note that the NSC has precedents for implementing targeted or risk-stratified screening programmes. For instance, cervical cancer screening incorporates HPV testing to identify and focus resources on higher-risk individuals. This model could be adapted to dementia, targeting groups such as:

• Those with a known genetic predisposition (e.g., familial FTD).

• People with learning disabilities, particularly Down syndrome, who have a higher lifetime risk of dementia. Around 30% of people with Down syndrome who are in their 50s have Alzheimer's dementia, rising to 50% for people with Down syndrome in their 60s.[viii] Absolute numbers of individuals affected are also likely to rise given increases in life expectancy for people with Down Syndrome.[ix]

• Individuals with significant cardiovascular risk factors, where vascular dementia prevalence is higher.

• Individuals who have been diagnosed with a condition with an associated dementia, such as Parkinson's disease or Huntington's disease.

6.4. By stratifying screening according to risk, the UK could begin to capture the benefits of early detection for those most likely to benefit, without incurring the costs and potential harm of universal screening.

7. Rethinking the 'lack of treatment' debate

7.1. The NSC's decision is partly based on the current absence of approved, disease-modifying treatments for dementia. Dementia UK argues against this as a primary reason to rule out screening.

7.2. Firstly, there is robust evidence that post-diagnostic support and interventions—such as carer education, advance care planning (ACP), and structured emotional support—can improve quality of life and reduce behavioural and psychological symptoms. These can empower families to make informed legal, financial, and care decisions at a time when the person with dementia can still participate meaningfully. This is consistent with the NSC's emphasis on the autonomy and well-being of individuals undergoing screening.

7.3. For example, when conducted in a timely and thorough manner, ACP can:

• reduce crisis-driven decisions

• reduce inappropriate hospital admissions and overtreatment

• relieve family members of the burden of making uninformed decisions during emergencies

• minimise confusion and distress during deterioration or at the end of life.[x]

7.4. Likewise, studies supporting the benefits of psycho-social interventions are noted in the committee papers.[xi] For example, music therapy has been shown to improve the thinking, feeling, perception, mood and behaviour of people living with dementia.[xii] Similarly, cognitive stimulation therapy, which involves a wide range of activities that aim to stimulate thinking and memory, has been proven to improve performance across various cognitive areas (memory, thinking, reasoning, attention, organising, planning, etc).[xiii]

8. The importance of including post-diagnostic support within the screening strategy.

8.1. The UK NSC's Ethical Framework for Screening emphasises the importance of mitigating the potential harm of screening.[xiv] For dementia, the potential harm lies not only in false positives or overdiagnosis, but in failing to provide adequate support after a positive screen.

8.2. We therefore urge the NSC to make post-diagnostic family support a core component of any screening strategy—whether targeted or universal. This should include:

• **Immediate referral to a dementia specialist** nurse (Admiral Nurse model) for holistic family support.

• **Carer education programmes** to help families understand symptoms, manage behaviours, and access benefits.

• **Emotional support and counselling** to address the psychological impact of diagnosis.

• **Structured advance care planning** to safeguard the wishes of the person with dementia.

8.3. The cost-effectiveness of screening is often measured in terms of treatment outcomes, but in dementia, it must also account for reduced carer breakdown, fewer crises, and less restrictive care pathways —outcomes directly influenced by the timeliness and quality of family support.

9. Conclusion

9.1. While we understand the Committee's caution in recommending against a population screening programme for dementia at present, we believe there is a practical imperative to plan for the near future. Early detection, even without a cure, can profoundly benefit people living with dementia and their families, provided it is matched with timely, comprehensive support.

9.2. The UK NSC's role is pivotal in ensuring that screening policy keeps pace with scientific developments while safeguarding patient well-being. We stand ready to work with the Committee and other stakeholders to ensure that when the time comes to implement screening, whether targeted or universal, it is underpinned by a robust infrastructure that places families at the heart of dementia care.

10. Contact us

Dementia UK is grateful for the opportunity to provide feedback. For more information, please contact XXX XXX, Policy Officer (Post-diagnostic Support), at xxxxx

September 2025

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11. XXX XXX, Association of British Neurologists (ABN)

Good afternoon

Please find the ABN comments to the following consultation. Thank you for including us in this.

Best wishes

XXX

Overall response	The report does not consider any benefit from screening specific population groups. In particular, we consider that screening with adults with specific diagnoses which predispose to dementia may be appropriate and warrants further evaluation. For example, in Down syndrome nearly all individuals develop Alzheimer's disease pathology by age 40 years, and approximately 70% are diagnosed with dementia by around age 54 years.[1] One-year post-stroke the prevalence of dementia is of the order of 20%.[2] And ~70% of people in care homes have dementia.[3] To not consider the benefits of screening specific groups where dementia is more likely is to miss the opportunity to start early treatment with appropriate licensed agents and provide appropriate support and care. 1. Rafii, MS et al. Down syndrome and Alzheimer's disease: insights into biomarkers, clinical symptoms, and pathology. Lancet Neurology, 2025 24(9): 753 – 762 2. Craig L, Hoo ZL, Yan TZ, *et al* Prevalence of dementia in ischaemic or mixed stroke populations: systematic review and meta-analysis *Journal of Neurology, Neurosurgery & Psychiatry* 2022;**93:**180-187 3. https://www.alzheimers.org.uk/about-us/news-and-media/facts-media While perhaps out of scope for this report, we would also highlight the need for high quality studies establishing accurate prevalence and incidence of dementia in the UK to inform future evaluations of screening. We would also counter some of the conclusions of this report:

	“There are no screening tests which could find people with dementia before they show symptoms” This is incorrect. There is good evidence that biomarker changes which can be shown using PET scans, CSF examinations and blood testing precede the development of clinical Alzheimer’s disease (although we agree that these are **not** currently suitable for implementation as screening tools). **“There is no evidence that current treatments for dementia are effective”** Whilst there are no commissioned disease modifying treatment for dementia, there are NICE approved symptomatic treatments for Alzheimer’s disease. However, we do not know if these would be effective in patients diagnosed by screening as trials were conducted in patients presenting with symptoms.

12. Dr Shahid H Zaman MD PhD FRCP FRCpsych, Director of the Cambridge Intellectual and Developmental Disabilities Research Group, Assistant Professor in Psychiatry of Intellectual Disability, Department of Psychiatry, University of Cambridge, Honorary Consultant Psychiatrist, Clinical Lead for Intellectual Disability Service, Cambridgeshire & Peterborough Foundation NHS Trust

Name:	Dr Shahid Zaman	**Email address:**	xxxxxx
Organisation (if appropriate):	DSMIG or Down Syndrome Medical Interest Group (https://www.dsmig.org.uk/)		
Role:	**Steering Committee Member at the DSMIG.** **Research lead (Assistant Professor) in dementia of intellectual disability at the University of Cambridge, Dept of Psychiatry**		
Do you consent to your name being published on the UK NSC website alongside your response? Yes			

Section and / or page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
No section was chosen as this topic is not covered by the current draft	Omission of people with learning disabilities ("intellectual disability" (ID)) including individuals with Down syndrome (DS). The most common form of dementia in DS is due to Alzheimer's disease which occurs in adulthood-some 10 to 20 years earlier than in the general population. Compared to the neurotypically developing population, dementia in people with ID occurs c. 10 years earlier and in some syndromes even earlier. Most of cases diagnosed with dementia amongst all people with ID who are under the age of 60yrs are seen in people with DS. Concerning questions regarding screening in this population, the current evidence suggests "baseline	Population screening for dementia in people with intellectual disability. The Version 1.7 of the UK National Screening Committee's report, "Population screening for dementia in adults" (Dementia - UK National Screening Committee (UK NSC) - GOV.UK) only addressed the typically developing population and not people with intellectual disability (ID), also termed "learning disability" including individuals with Down syndrome (DS). The conclusion of the draft report was, "…the findings of this evidence map appear unlikely to impact the current recommendation not to screen for dementia as no new evidence was identified that would change this recommendation." Here we provide an informed view of the value of screening for the prodromal stage of dementia ("MCI") and dementia in this population.

	assessments" to establish pre-morbid functioning. Regarding screening, the conclusions reached in the draft would concur with our views.	Dementia in DS is a genetic form of Alzheimer's disease as it is fully penetrant by virtue of the triplication of the Amyloid Precursor Protein (APP) gene. The autosomal dominant form of Alzheimer's disease (another genetic form of the disease) is caused by, for example, mutations in the APP gene which is found in families in the general population and who do not have DS. These two genetic forms of Alzheimer's disease are similar in their natural history and pathological trajectory (including for biomarkers). By the age of 65 years, almost 90% of people with DS will have a diagnosis of Alzheimer's disease (McCarron et al., 2014). Dementia in this population is the underlying cause of death in more than 70% of adults aged over 35 years with DS (Hithersay et al., 2018). Age is a major risk factor for dementia and people with DS are living much longer than they were in the 1970s and prior; the median age if death was 58 years by 2011 (Wu et al., 2011). The diagnosis of DS can be challenging (including in people with ID who do not have DS) due to the premorbid intellectual disability that varies considerably from person to person (from mild, to moderate, to severe, to profound). A "screening tool" will thus be a measure of the degree of ID and the new onset of functional change. This can lead to diagnostic overshadowing, or the misattribution of a given clinical presentation to the intellectual disability and not a specific, medical, psychiatric or other cause. Co-morbidities associated with DS need to be systematically considered before it can be concluded that the diagnosis is dementia and a key piece of evidence that is sought is a change in functioning from the pre-morbid state. Unlike in the general population where there are well established psychometric tests with

		normative or reference values available to help interpret measures of cognitive functioning, for DS (and other forms of ID) there are no such tests available. Consequently, the key features that are necessary to support the case for a diagnosis of dementia are, evidence for decline in cognition and in activities of daily living. The recently published UK guidelines, "Dementia and People with Intellectual Disabilities Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia" (by the British Psychological Society and the Royal College of Psychiatrists; https://cms.bps.org.uk/sites/default/files/2022-09/Dementia%20and%20People%20with%20Intellectual%20Disabilities.pdf) recommends the establishment of a baseline of cognitive functioning using assessment tools designed for people with DS or intellectual disability (such as, CAMDEX; DSQIID; DLD). However, this is not to be considered as "screening" but a reference measure that can be used to compare and detect or confirm a decline in functioning in the future or when there is a clinical concern or when dementia is suspected. The same principles apply to diagnosing dementia in the non-DS ID population. Whereas, the most common form dementia in DS is the Alzheimer's disease-type, the non-DS ID group can be expected to have the same range of dementias as those that are seen in the general typically developing population (Alzheimer's disease, vascular dementia, Lewy body disease etc.) but occurring at an earlier age by about a decade. The UK guideline (https://cms.bps.org.uk/sites/default/files/2022-09/Dementia%20and%20People%20with%20Intellectual%20Disabiliti

		es.pdf) recommends baseline assessments at the age of 50 years for the non-DS ID population. There are some genetic syndromes associated with ID where the onset of dementia is a younger age (such as 22q11 deletion syndrome (22q11.2DS), Fragile X syndrome and Tuberous Sclerosis Complex: Boot et al., 2023; Vingerhoets et al., 2024; Sauna-aho et al., 2020; Evers et al., 2014; Hwang et al., 2023). Such conditions would benefit from establishing baseline measures at a younger age. It is recommended that primary care services provides annual health checks for people with ID. This provides an opportunity to establish baseline measures of function. Regarding screening, the draft document addresses the three questions by scoping the evidence. The evidence in the field of dementia for people with ID is more limited and less advanced than that in the neurotypical population. It will take several more years before disease modifying treatments are available as we await the results of clinical trials that are being conducted or proposed for benefit of the ID (especially DS) populations. In conclusion, it is important to undertake baseline assessments in people with DS and intellectual disability as this improves the diagnostic accuracy. REFERENCES

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13. XXX XXX, Secretariat, Dementia Industry Group

Section and/or page number	Text or issue to which comments relate	Comment
General	General	This submission has been developed by the Dementia Industry Group (DIG). The DIG is a life sciences industry collaborative group, supporting the UK to lead in the field of dementia diagnosis, treatment and research. The DIG's membership comprises Biogen, Eisai, Lilly, Roche Diagnostics and InHealth Group.
Page 15	Recommendation to review in 3-years' time	There is a significant and growing burden of dementia in the UK, impacting on patients, their loved ones, the NHS, and society more broadly. Dementia is already the UK's leading cause of death[1] and the scale of the challenge makes this an area in which the government has a significant opportunity to transform care and change lives. Innovation in dementia care and treatment has transformative potential and we are on the precipice of realising significant, positive changes in the way in which the disease is diagnosed and managed. To realise this potential and to enable the UK to be a genuine world-leader in dementia care, a step change is urgently needed in the way dementia is approached across the UK. The development of blood-based biomarkers is revolutionising dementia diagnosis, enabling earlier, more accurate, and less invasive detection of Alzheimer's and related conditions. Blood-based biomarkers could significantly improve the speed, accessibility, and equity of diagnosis across the NHS.[2] More should be done to prepare the health system for access to innovation, including better access to diagnostics to identify eligible patients before disease progression. This is aligned with the ambition set out in the Government's Life Sciences Sector Plan to grow the economy and transform the NHS to get new treat-

		ments to patients faster. Earlier access to diagnosis also enables patients to access research opportunities and enables best supportive care through existing pathways. These emerging innovations should inform the Committee's decision-making, through timely re-consideration of evidence in the dementia landscape and the evolutions that are under-way in relation to the management of dementia. The Dementia Industry Group would strongly support a shorter review window of 18 months, to ensure the UK National Screening Committee's evidence map and recommendations keep pace with forecast change in dementia treatment and diagnostics. Doing so will help to support the ambition for the UK to be at the forefront of dementia diagnosis and outcomes.
Page 5	Background and objectives	The Dementia Industry Group recognises that current evidence does not support a recommendation on population screening for dementia. Moving forward, there is a case for the Committee to consider screening for cognitive change more broadly, which would impact on dementia patients and those at risk of dementia, whilst also enabling different approaches to managing brain health more broadly. Dementia research underlines that changes to the brain take place many years before the onset of dementia symptoms, which enables a significant window for earlier intervention in the form of lifestyle changes.[3] The Dementia Industry Group would be supportive of a broadened scope for screening, which may offer a better return in relation to population health management, prevention, and efforts to delay onset, which will be increasingly significant in the context of an ageing population and growing dementia burden.

		At the same time, screening could also enable earlier identification of dementia patients – with resulting opportunities to support people to make lifestyle changes; access clinical trials and research opportunities; and benefit from future innovation.
Page 5	Aims of the evidence map	The current scope of the evidence map does not consider the evolving landscape in models of care for dementia and the opportunities that may arise for population screening in the context of broader health policy initiatives. For example, emerging models of care – such as neighbourhood health teams and enhanced use of digital and AI tools – will have an impact on the management of dementia patients and opportunities to support improved outcomes following diagnosis. The Dementia Industry Group would support further reflection from the Committee on the current models of care for dementia patients and how these could be leveraged to enhance care for patients – and the bearing this may have on acceptability of screening. This could also extend to the consideration of the opportunities to pilot screening methodology and/or integrate screening into existing pathways (such as the NHS Health Check) to better identify patients at risk of dementia earlier. Recent evidence underlines that modifying 14 risk factors over the life course could prevent nearly half of global dementia cases.[4] To this end, the integration of simple tests into existing health check programmes – such as hearing tests, cholesterol tests, cognitive testing, and future adoption of blood testing – could support risk factor modification to prevent dementia cases and delay onset. The Group underlines the scope for learning from other UK screening programmes that have been developed through pilot models and that have successfully targeted certain at-risk demographics, such as the NHS lung health check.

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UK National Screening Committee

14. Luke Symons, Policy Officer, Alzheimer's Society

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Role:	Policy Officer		
Do you consent to your name being published on the UK NSC website alongside your response? Yes			

Section and / or page number	Text or issue to which comments relate	Comment *Please use a new row for each comment and add extra rows as required.*
Page 15	"On the basis of this evidence map, the volume and type of evidence related to screening for dementia appears insufficient to justify commissioning an evidence summary at this stage. We recommend that this topic should be re-considered in 3-years' time."	We support the recommendation of the review and agree that there is insufficient evidence at this time to recommend commissioning a more detailed evidence summary or to recommend screening for dementia. The UK National Screening Committee's criteria for population screening programme states that there should be evidence from high quality randomized controlled trials that the screening programme is effective in reducing mortality or morbidity. Despite some omissions that we have identified in the evidence presented in this review, which we will highlight further in this response, we agree that the current evidence base does not meet the 'gold standard' for recommending population-level screening. Therefore, we agree that the current evidence base does not support a change in the committee's recommendation. We also support re-consideration of this topic in three years' time.

		Considering ongoing research into the development and validation of new diagnostic tools including blood tests, clinical trials of treatments in asymptomatic populations, and studies investigating non-pharmacological approaches to delaying disease progression, it currently appears that a review in three years' time would be appropriate. However, given the volume of research currently underway in this space, some of which we highlight further in our response, we recommend that the UK National Screening Committee continue to monitor the research landscape and consider conducting the next review sooner if merited by the pace of developments. In future reviews, we would also recommend exploring more recent evidence on public attitudes to the acceptability of population screening for dementia. We note that this was included in the last full evidence review conducted in 2018/19 but not revisited in this iteration.
Page 3	"Question 1: What is the volume and type of evidence available on the accuracy of screening tests used to detect MCI and/or any type of dementia" This comment applies to the whole section for Q1 summary of findings.	Though we agree with the conclusion of question one's summary, that there continues to be a lack of evidence to support population screening for dementia, we would like to seek further clarity on the rationale for the inclusion and exclusion of certain types of evidence. We would be keen to engage the committee directly on this point, to develop a greater understanding on the nature of the evidence examined as part of this review, so that we might better support the committee's work moving forward. If members of the committee would welcome it, we would happily meet to discuss this further.

		We notice that evidence pertaining to blood biomarkers was not reviewed as part of this exercise, and would welcome further information on the rationale for this - whether this was due to a lack of studies examining the accuracy of blood biomarkers in individuals living in the community and not suspected to have dementia, or due to an oversight in search terms, or another reason. We note that search terms included in the review's protocol and search criteria outlined in appendix 1 included the search term 'Biomarkers exp', however other search terms such as 'blood test' were omitted. It is worth highlighting here the Blood Biomarker Challenge. This is a collaborative multi-million pound programme supported by Alzheimer's Society, Alzheimer's Research UK and the National Institute for Health and Care Research (NIHR), Gates Ventures, and players of the People's Postcode Lottery. It hopes to revolutionise dementia diagnosis in the UK by piloting the use of these blood tests in the NHS, with research teams examining how these blood tests perform in real world setting to diagnose symptomatic patients. While further research is still needed to understand their potential clinical utility to meet the criteria of an accurate screening test, their high accuracy, practicality and low costs mean that they have significant potential to become the tool of choice for a national screening programme in the future.

Page 3	Question 1 in general, but related to "A limitation of the review is that patient characteristics were not reported."	We would recommend considering a wider review of cognitive assessment instruments to ensure the next review provides a more comprehensive assessment of those tools available and also considers patient characteristics. We know that generally in research, participant populations are not often diverse which may be why some studies examined didn't include patient characteristics in their reporting, or data on patient characteristics may not have been available to these research teams. However, examining studies of cognitive assessment tools where patient characteristics are not reported, limits what can be learnt about the impact these characteristics can have on responses to the assessment. Factors such as culture and language can affect assessment outcomes, so these are important considerations when assessing the performance of these tools in different populations. Many Memory Assessment Services use tests such as the Rowland Universal Dementia Assessment Scale (RUDAS), or modified versions of other available cognitive tests to help minimize the effects of cultural learning and language diversity on the assessment of baseline cognitive performance. While all cognitive tests have their own limitations, a fuller review of the array of tests available will help to build a more comprehensive picture on potentially utility for population screening.
Page 16	Comments apply to 'Appendix 1: search strategy for the evidence map' in general, and 'Search strategies: Screening tests search' and 'Search strategies:	Comments here relate broadly to the search criteria used in the search strategies for screening tests, and pharmacological and non-pharmacological interventions.

	Pharmacological and non-pharmacological interventions search' specifically.	We note that commonly used terms for people who are asymptomatic or presymptomatic were omitted from search criteria. These include but may not be limited to: 'preclinical', 'subjective cognitive impairment', and 'memory complaints'. Additionally, given the search is looking for people who are asymptomatic, those people could also be described as 'healthy individuals' in relevant literature. We would suggest considering including additional search terms such as these.
Page 7	'Pharmacological treatments for A D have shown mixed outcomes. Donanemab and lecanemab offer some promise, as they appear to slow cognitive and functional decline in early A D. However, these benefits come with significant safety concerns that need careful consideration. Other disease-modifying drugs such as gantenerumab, zagotenemab, tilavonemab, neflamapimod, and solanezumab did not show efficacy in slowing clinical or cognitive decline.'	We agree with the conclusion of the outcomes/findings section for pharmacological interventions examined as part of question 2. We would however highlight NICE's conclusion of their appraisal of lecanemab and donanemab where they state that, whilst benefits were small, both treatments have been shown to delay progression from mild to moderate Alzheimer's disease by four to six months and that any slowing of disease progression would be meaningful for people with MCI or mild dementia caused by Alzheimer's disease.
Page 12	'In conclusion, the volume of potentially relevant new evidence is large but pharmacological interventions evaluated in randomised controlled trials have yet to demonstrate meaningful benefits for people with preclinical or early symptomatic dementia, especially when safety concerns and associated costs are taken into account. There are large numbers of new	We agree with the conclusion of the outcomes/findings section for non-pharmacological interventions examined as part of question 2.

	systematic reviews and trials of non-pharmacological interventions for people with M C I but many of these are complex and/or experimental and links with population screening are lacking.'	
Page 13	'Question 3: What is the available evidence of active research or developments (including clinical trials, observational studies, evidence syntheses, patents or opinions) investigating: - Innovative screening tests, diagnostic tools, care pathways or risk assessment approaches for MCI and dementia. - Novel interventions (both pharmacological and non-pharmacological) to prevent, delay or treat MCI and dementia.'	As highlighted in an earlier comment, we would suggest that blood biomarkers and blood tests may be an omission under 'innovative screening tests, diagnostic tools, care pathways or risk assessment approaches for MCI and dementia'. We would recommend the inclusion of evidence and research in this area as part of the next review.
Page 13	'Question 3: What is the available evidence of active research or developments (including clinical trials, observational studies, evidence syntheses, patents or opinions) investigating: - Innovative screening tests, diagnostic tools, care pathways or risk assessment approaches for MCI and dementia. - Novel interventions (both pharmacological and non-pharmacological) to prevent, delay or treat MCI and dementia.'	We would also recommend the inclusion of evidence examining effectiveness of emerging technologies for the detection of early dementia symptoms, when conducting the next review. There are emerging technologies – such as language change detection tools, VR navigation, and artificial intelligence powered mobile apps – that could yield interesting results worth investigating further. For some diseases that cause dementia, these are among the earliest symptoms to change.
Page 13	'Question 3: What is the available evidence of active research or developments (including clinical trials,	For consideration of 'novel interventions (both pharmacological and non-pharmacological) to prevent, delay or treat MCI and

	observational studies, evidence syntheses, patents or opinions) investigating: - Innovative screening tests, diagnostic tools, care pathways or risk assessment approaches for MCI and dementia. - Novel interventions (both pharmacological and non-pharmacological) to prevent, delay or treat MCI and dementia.'	dementia' we would highlight this paper, 'Alzheimer's disease drug development pipeline: 2025' by Jeffery L. Cummings. This paper is an annual update from the Clinical Trial Observatory. Key findings from this include: - There are 138 drugs in 182 clinical trials in the drug development pipeline for Alzheimer's disease. - There are 31 drugs in Phase III trials, of which 12 were due to finish in 2025. - There are 4 prevention trials in Phase III. - There are 6 trials for MCI/prodromal participants. The number of drugs in clinical trials for Alzheimer's disease is increasing year on year and includes targets across all features of the disease in the brain. In addition, trials in the pipeline cover all clinical stages of the disease from asymptomatic at-risk to severe dementia.

UK National Screening Committee

15. XXX XXX, GP, Royal College of General Practitioners

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Do you consent to your name being published on the UK NSC website alongside your response?			

Section and / or page number	Text or issue to which comments relate	Comment *Please use a new row for each comment and add extra rows as required.*
P5 Background and Objectives Paragraph 3	A general cognitive screening test is not appropriate in MCI/people at risk of dementia; one needs to focus on executive function and visuospatial domains It is not only screening for cognition that is relevant in people at risk of dementia but also behavioural symptoms The Mild Behavioral Impairment Checklist (MBI-C): A Rating Scale for Neuropsychiatric Symptoms in Pre-Dementia Populations J Alzheimers Dis . 2017;56(3):929-938. doi: 10.3233/ JAD16097	We recommend that general cognitive screening tests are not used for people with mild cognitive impairment (MCI) or those at risk of dementia. Screening should focus on executive function and visuospatial domains, as well as behavioural symptoms. Tools such as the Mild Behavioral Impairment Checklist (MBI-C) can provide valuable insights in pre-dementia populations (Ismail et al, *J Alzheimers Dis*. 2017;56(3):929–938. doi:10.3233/JAD16097).
P6 Question 1	What is the volume and type of evidence available on the accuracy of screening tests used to detect M C I and/or any type of dementia?	We suggest the development of national guidance to address variation in diagnostic and therapeutic practice. This should cover the use of neuroimaging, fluid biomarkers, cognitive testing, follow-up, and diagnostic terminology in MCI. We note that MCI is a heterogeneous clinical syndrome, not a diagnosis in its own right, with 5–15% progressing to dementia annually. Decisions about investigation and biomarker use should be individualised. However, as with dementia, routine blood

		screening and structural imaging are appropriate in those with objective decline (Livingston et al, *Age and Ageing* 2020; doi:10.1093/ageing/afaa228).
P6 Aim of project	The aim was to address the following questions:	We recommend prioritising screening for people "at risk" of dementia, particularly those with multimorbidity, rather than pursuing population-level screening. Evidence shows multimorbidity is strongly associated with poorer brain health, especially in cardiometabolic clusters (Stirland et al, *Alz Dement* 2025; doi:10.1002/alz.70546; Al Abid et al, *J Prev Alz Dis* 12, 2025;100208). Cardiovascular comorbidities including hypertension, diabetes, heart failure, and stroke account for a significant proportion of incident dementia cases (Klee et al, *Alz Dement* 2025; doi:10.1002/alz.14589). Screening those with multimorbidity could be embedded within routine annual long-term condition reviews in primary care.
P7 Paragraph 2	For question 1 (accuracy of screening tests), we included studies of the accuracy of any type of screening test in people living in the community and not already suspected of having dementia or M C I. Studies of people with a co-morbidity that could affect cognitive performance were excluded. The reference standard for diagnostic accuracy was a formal diagnosis of M C I or dementia using recognised criteria.	We suggest that screening approaches incorporate data on comorbidities and the heterogeneity of MCI, as outlined above.
P7 Paragraph 3	Outcomes of interest included but were not limited to reduced cognitive decline, improved physical function, reductions in depression and challenging behaviour, improved independence and quality of life, and	We note the importance of considering hippocampal volume and long-term effects of lifestyle interventions. The 11-year follow-up of the FINGER trial demonstrated sustained cognitive and lifestyle benefits after a 2-year multidomain intervention,

	reductions in mortality.	particularly among adherent participants (Kivipelto et al, AAIC 2025). These findings highlight the value of prevention, adherence, and ongoing support.
P13 Question 1 2nd paragraph	...as well as the Mini–mental state examination (MMSE), have good sensitivity and specificity in screening for MCI in primary care. The	We recommend against using the MMSE to identify MCI or mild dementia, as it has significant floor and ceiling effects (Sánchez-Rodríguez et al, *Int Psychogeriatrics* 2010;22(1):72–81).
P17 Question 2 Outcomes Findings paragraphs 1	Melatonin was significantly more effective than donanemab (standardised mean difference (S M D) –1.73 (–3.22 to –0.25)), lecanemab (–1.85 (–3.27 to –0.42)), aducanumab (–2.02 (–3.47 to –0.56)), and placebo (–2.27 (–3.42 to –1.12)) on cognitive function.	We caution against conflating symptomatic therapies such as melatonin with disease-modifying therapies (DMTs). Melatonin may improve sleep and indirectly benefit cognition, but DMTs target underlying pathology. These represent fundamentally different therapeutic strategies.
P17 Question 2 Outcomes Findings paragraphs 5	Pharmacological treatments for A D have shown mixed outcomes. Donanemab and lecanemab offer some promise, as they appear to slow cognitive and functional decline in early A D. However, these benefits come with significant safety concerns that need careful consideration. Other disease-modifying drugs such as gantenerumab, zagotenemab, tilavonemab, neflamapimod, and solanezumab did not show efficacy in slowing clinical or cognitive decline	We understand that previous amyloid therapy trials have failed, largely due to late intervention, narrow targeting, trial design flaws, and inadequate patient selection. Future therapies must account for the multifactorial nature of disease (Boxer et al, *Cell* 186, 2023; doi:10.1016/j.cell.2023.09.023).
P18	Non-pharmacological interventions	We suggest continued investment in non-pharmacological interventions. The long-term FINGER data, along with other prevention studies, show that lifestyle and behavioural interventions can deliver durable cognitive benefits (Rasmussen et al, *Management of Early Alzheimer's Disease*, Elsevier, 2025).

P23 last paragraph	In conclusion, the volume of potentially relevant new evidence is large but pharmacological interventions evaluated in randomised controlled trials have yet to demonstrate meaningful benefits for people with preclinical or early symptomatic dementia, especially when safety concerns and associated costs are taken into account.	We recognise that lecanemab has shown clinically meaningful benefits in early Alzheimer's disease. At 36 months, treatment reduced cognitive decline (CDR-SB -0.95 vs expected decline) and in some cases enabled functional recovery, such as driving or returning to work (AAIC 2024; Scrip Citeline SC150672).
P23 last paragraph	especially when safety concerns and associated costs are taken into account.	We note that subcutaneous lecanemab offers an improved safety profile compared to IV administration. At AAIC 2025, subcutaneous dosing showed <1% systemic reactions compared to 26% with IV, with no ARIA-E cases reported in maintenance therapy. This route may increase accessibility and safety.
P25	Recommendations	We recommend validated dementia risk assessment tools, such as CAIDE and the Framingham Risk Score, be incorporated into clinical practice. The CAIDE score is particularly useful in midlife (40+) and uses routinely collected data from long-term condition management, making it practical in primary care. Incorporating such tools could help identify those with MCI at highest risk of progression (Hua et al, *Age Ageing* 2022;51(12):afac282; Kasim et al, *Lancet Reg Health West Pac* 2023;35:100742; Chis et al, *BMJ Open* 2015;5:e007142).

16. XXX XXX, Policy Advisor, Alzheimer's Research UK

Alzheimer's Research UK is the UK's leading dementia research charity, striving for a cure by revolutionising how we treat, diagnose and prevent dementia. As an organisation committed to public health, we will continue to advocate for the prevention, earlier diagnosis and equitable access to innovations that reduce dementia risk and improve lives across the UK. We provide relevant, robust evidence to inform the Committee's review, grounded in our research expertise.

We support the UK National Screening Committee's current stance against dementia screening, since currently no new evidence would change this view. We also agree with not commissioning a full evidence summary for now. However, given the rapidly evolving evidence base and rising dementia prevalence – from 1 million people in 2024 to a projected 1.4 million by 2040 (1) – we believe this topic should be reviewed sooner than the standard three-year time frame.

Addressing 14 modifiable risk factors could prevent or delay up to 45% of dementia cases globally (2). To turn that potential into practice, the NHS needs reliable, acceptable and equitable ways to identify people at higher risk earlier and link them to proven risk reduction and diagnostic pathways. Since the last NSC review, primary care risk models, NHS pilots of blood biomarkers and scalable digital tools have moved from concept to early implementation studies.

The evidence and recommendations we set out below are intended to inform the Committee's ongoing review of evidence related to whether to introduce population screening for dementia or not.

Frequency of evidence review:

Our submission sets out examples of promising evidence that the Committee should consider adding to their evidence map, UK-focused evidence on:

• Mild Cognitive Impairment best practice

• Emerging blood biomarkers and trials

• Population burden

• Public attitudes

• Promising risk-prediction models.

Given the rapidly expanding evidence base, we recommend that the UK NSC's reviews the evidence relating to population screening for dementia annually or move to a rolling review so that new findings can be assessed promptly and reflected in updated UK NSC screening recommendations.

Mild Cognitive Impairment: Clinical definition and scope:

Given ongoing variability in how mild cognitive impairment (MCI) is defined, diagnosed and managed, we recommend the Committee explicitly recognise the need for national clinical guidance on MCI from bodies like the National Institute of Health and Care Excellence, using the Manchester Consensus (3) as a reference point.

This Consensus:

• Identifies the need for practical, UK-focused guidance to standardise the definition, assessment and management of MCI, including how other, often treatable causes of cognitive impairment (vascular, metabolic, psychiatric, sleep) should be addressed – which can change care and improve outcomes even when Alzheimer's pathology is absent.

• Emphasises clear terminology, investigation of reversible causes, risk stratification, shared decision-making, and structured follow-up/referral pathways.

Population screening for dementia would involve offering people living in the community and not suspected of having dementia a rapid cognitive assessment test. Those who screen positive would undergo a full diagnostic assessment and would be able to access support from health and social care services while the disease was at a relatively early stage. The National Institute for Health and Care Excellence (NICE) has published guidance on dementia (NG97) (4), covering assessment, management and support for people living with dementia and their carers.

Biomarkers and therapeutic pipeline:

To inform the Committee's next review, we support inclusion of the following research to be added to the evolving evidence landscape.

• The Blood Biomarker Challenge, a five-year UK multi-centre programme led by Alzheimer's Research UK which assesses how blood tests (e.g., for biomarkers linked to Alzheimer's disease p-tau, NfL, GFAP) can be validated, quality-assured and embedded in NHS pathways(5).

• To situate diagnostics alongside treatments, the annual Cummings pipeline analysis quantifies the therapeutics landscape (currently 164 active trials, 127 unique therapies, ~76% disease-modifying) and highlights growing biomarker-guided enrolment (6).

• The 2024 Lancet Standing Commission on Dementia Prevention, Intervention and Care sets out 14 modifiable risk factors that may account for up to 45% of global cases and offers practical recommendations for risk reduction.(2)

• Ongoing late-stage, pre-symptomatic trials signal a shift toward earlier, biomarker-guided intervention:

o AHEAD 3-45 (lecanemab) uses plasma biomarkers, including p-tau, to pre-screen cognitively unimpaired, amyloid-positive adults (7).

o TRAILRUNNER-ALZ 3 (remternetug) evaluates disease-progression delay in early or pre-symptomatic Alzheimer's with biomarker-guided enrolment and subcutaneous dosing (8).

o TRONTIER (trontinemab) tests whether enhanced blood–brain-barrier delivery improves outcomes, building on early evidence of rapid amyloid clearance and p-tau reduction (9).

Taken together, this collection of evidence provides the Committee with up-to-date information on clinical validity, feasibility and clinical readiness of biomarker-enabled approaches.

Population impact and system levers:

We recommend adding the following key statistics to show the growing impact of dementia, and the need to keep screening and case-finding under periodic review. We believe this will help set the Committee's evidence in context.

• The projected future prevalence of dementia in the UK, projected to increase from 1 million people in 2024 to 1.4 million by 2040 (1).

• The latest Office for National Statistics mortality figures where dementia and Alzheimer's disease are the leading cause of death in England and Wales. These show 66,876 deaths registered, accounting for 11.6% of all deaths (10).

Public attitudes and engagement:

To inform the Committee's next review, we support inclusion of Alzheimer's Research UK's Dementia Attitudes Monitor (DAM) (11). The DAM is a nationally representative, biennial survey of 2,530 UK adults, disaggregated by age, sex, ethnicity and deprivation, demonstrating:

• Awareness and understanding of dementia and prevention. For example, 65% of people disagreed that dementia is an inevitable part of getting older.

• Willingness to seek a formal diagnosis. For example, 89% of adults would be likely to seek a formal diagnosis of dementia.

• Acceptability and likely uptake of testing (including blood tests). For example, regarding pre-symptomatic testing, 87% of respondents said they would take a test (53% regardless of treatments available; 16% only with effective prevention; 18% only with effective treatment).

• Beliefs about personal risk and risk-reduction behaviours. For example, 76% of adults without a dementia diagnosis would want to know their personal risk of developing it later in life.

• Stigma, barriers and enablers to seeking help. For example, among those respondents unlikely to seek a dementia diagnosis, 7% said because the “stigma is too great”.

• Communication needs (preferred messaging, channels, trusted messengers). For example, a recorded openness to digital channels for delivering/monitoring risk information was observed. 77% of adults were willing to use smartphone apps/wearables to receive this data.

DAM findings provide up-to-date, nationally representative evidence of how the public views dementia. We believe it’s inclusion in the Committee’s next evidence map would help inform future decisions on dementia screening.

Risk prediction tools:

To inform the Committee’s next review, we also support inclusion of the following risk-prediction evidence:

• DemRisk is a UK risk-prediction model for dementia, developed with Alzheimer’s Research UK funding and externally validated on 1,329,340 adults from Clinical Practise Research Datalink – a large UK primary-care electronic health-record resource. It shows good 5-year discrimination and outperforms an existing Electronic Health Record tool using routine GP data (12).

• Multiorgan risk prediction (developed using data from 228, 240 adults in the UK Biobank). This uses routine NHS Health Check variables (for example measuring blood pressure, total cholesterol) and reports strong 10-year discrimination for dementia alongside cardiovascular, kidney and liver outcomes (13). It offers a practical route to add a brain-health element to the NHS Health Check – a free five-yearly check for adults 40–74 to assess and manage risk of conditions including dementia, delivered in primary care (14).

Such research aligns with the Government's 10-Year Health Plan(15) by using AI (and, in time, genomics) to personalise prevention and earlier diagnosis within routine care. Both studies remain at the research-stage and before integration into NHS pathways, they require external validation and equity testing across diverse populations. Alzheimer's Research UK keeps an active interest in emerging evidence in this area given the potential for risk prediction tools to revolutionise earlier detection and targeted prevention approaches.

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(15) https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future