

UK National Screening Committee

Screening for Dementia

27 February 2019

Aim

1. To ask the UK National Screening Committee (UK NSC) to make a recommendation, based on the evidence presented in this document, whether or not screening for dementia meets the UK NSC criteria for a systematic population screening programme.

Current recommendation

2. The 2014 UK NSC review of screening for dementia concluded that systematic population screening should not be recommended.

The conclusions from this review were that:

- Cognitive assessment tools are not sufficiently accurate to be used in primary care or community care settings. Optimum cut-off levels are uncertain and all of the 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 is particularly poor. This means that the majority of people with a positive screening test result will 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 is often inconsistent or inconclusive. When statistically significant, the effects seen are small and their clinical significance remains to be ascertained.
- Evidence from US studies suggests that the uptake of further diagnostic testing among those with a positive screen result is low, though it is not clear whether this would also be the case within a UK context.

Evidence Summary

3. The 2018 evidence summary was undertaken by Solutions for Public Health, in accordance with the triennial review process: <https://legacyscreening.phe.org.uk/dementia>
4. The 2018 evidence summary addresses questions relating to the clinical prognosis of MCI and its association with dementia, the accuracy of cognitive assessment tools, biomarkers and brain imaging as screening tests, the effectiveness of pharmacological and non-pharmacological interventions after a screen detected diagnosis of MCI or dementia, and whether screening for MCI and/or dementia is clinically, socially and ethically acceptable to health professionals and the public. The review aims to assess whether the volume and direction of the evidence produced since the 2014 UK NSC review is sufficient to reconsider the current UK NSC recommendation on screening for dementia.
5. The conclusion of the 2018 evidence summary is that the current recommendation, that whole population screening for dementia should not be introduced in the UK, should be retained. This is for the following reasons:
 - Dementia is an important health problem. However, the prognosis of MCI and sub-types of MCI, in relation to the development of dementia remains unclear. The lack of a clinical definition for MCI adds to the difficulty in determining aetiology, predictors of conversion to dementia and overall



prognosis of the condition. As such MCI would not provide a reliable 'early predictor' of future dementia. **Criterion 1 not met**

- There remains a lack of evidence that cognitive assessment tools for MCI and dementia could provide an effective approach to population screening in the UK population. Overall the studies examining performance of cognitive assessment tools for MCI and dementia reported by 4 good quality meta-analyses were small with high heterogeneity due to cultural, social and geographical variations.

Moreover, MCI detected as an incidental finding of a dementia screening tool may represent a potential source of over detection, which had not been quantified. No studies explored the clinical utility of the cognitive assessment tools. In addition, no studies were identified that examined the effectiveness of the use of biomarkers and brain imaging tools to detect MCI or dementia in adults living in the community who are not already suspected of having dementia or MCI. Current evidence on biomarkers for dementia and MCI is largely focussed on their application to confirm an already suspected diagnosis. **Criteria 4 and 5 not met**

- In line with the findings of the previous review, no studies examining pharmacological or non-pharmacological treatments in people with screen detected MCI or dementia were identified. The review provided a brief general discussion of the evidence relating to interventions in non screen detected dementia. This reported the lack of strong positive evidence of benefit from the treatments. **Criteria 9 and 11 not met**
- Studies that describe perceptions, attitudes and views about screening for dementia point towards mixed views reported by the general public and healthcare professionals. In particular dementia specialists were generally opposed to the idea of screening for dementia. **Criterion 12 not met**

Consultation

6. A three month consultation was hosted on the UK NSC website. Direct emails were sent to 12 stakeholder organisations. Staff from a further organisation submitted comments without prior contact. **Annex A**

7. Comments were received from the following six stakeholders:

- i. Alzheimer's Research UK
- ii. Alzheimer's Society
- iii. Association of British Neurologists (Cognitive Advisory Group)
- iv. British Geriatrics Society
- v. Royal College of Physicians
- vi. Two members of staff at University Hospitals of Leicester NHS Trust

(See **Annex B** for comments)

8. All of the stakeholders that were contacted directly agreed with the overall conclusion of the review that it is not currently appropriate to implement a national screening programme for dementia.

9. The following points were also made:

- The review correctly highlighted the need for further research in areas where the evidence base is currently insufficient or unclear: particularly, the relationship between MCI and dementia, biomarkers and imaging techniques, the acceptability of screening for dementia in the UK.
- One stakeholder outlined that looking to future reviews, it would be important to consider the increasing research focus on biomarkers to detect asymptomatic stages of dementia in order to explore potential disease-modifying treatments that would delay or stop cognitive decline.



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- One stakeholder was concerned that the review's conclusion may impact on current recommendations and funding for testing for dementia in acute settings.

Response: This last comment refers to the use of tests to assess acutely unwell older patients. The scope of the UK NSC review covers the systematic 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 acutely ill older people in hospital settings.

Recommendation

10. The Committee is asked to approve the following recommendation:

Systematic population screening for dementia is not recommended as a population screening programme in the UK.



Criteria (only include criteria included in the review)	Met/Not Met
Section 1 - Criteria for appraising the viability, effectiveness and appropriateness of a screening programme	
The Condition	
1. The condition should be an important health problem as judged by its frequency and/or severity. The epidemiology, incidence, prevalence and natural history of the condition should be understood, including development from latent to declared disease and/or there should be robust evidence about the association between the risk or disease marker and serious or treatable disease	Not Met
The Test	
4. There should be a simple, safe, precise and validated screening test.	Not Met
5. The distribution of test values in the target population should be known and a suitable cut-off level defined and agreed.	Not Met
The Intervention	
9. There should be an effective intervention for patients identified through screening, with evidence that intervention at a pre-symptomatic phase leads to better outcomes for the screened individual compared with usual care. Evidence relating to wider benefits of screening, for example those relating to family members, should be taken into account where available. However, where there is no prospect of benefit for the individual screened then the screening programme shouldn't be further considered.	Not Met
The Screening Programme	
11. There should be evidence from high quality randomised controlled trials that the screening programme is effective in reducing mortality or morbidity. Where screening is aimed solely at providing information to allow the person being screened to make an "informed choice" (such as Down's syndrome or cystic fibrosis carrier screening), there must be evidence from high quality trials that the test accurately measures risk. The information that is provided about the test and its outcome must be of value and readily understood by the individual being screened.	Not Met
12. There should be evidence that the complete screening programme (test, diagnostic procedures, treatment/ intervention) is clinically, socially and ethically acceptable to health professionals and the public.	Not Met

List of organisations contacted

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

Screening for dementia

Consultation comments

1. Alzheimer's Research UK

Name:	Susan Mitchell	Email address:	xxxx xxxx
Organisation (if appropriate):	Alzheimer's Research UK		
Role:	Policy Manager		
<p>Do you consent to your name being published on the UK NSC website alongside your response?</p> <p style="text-align: center;">Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p>			
Section and / or page number	Text or issue to which comments relate	Comment	
		<i>Please use a new row for each comment and add extra rows as required.</i>	
Introduction		Alzheimer's Research UK (ARUK) is the world's leading dementia research charity dedicated to researching the causes, diagnosis, prevention, treatment and cure of dementia. Backed by our passionate scientists and supporters, we're challenging the way people think about dementia, uniting the big thinkers in the field and funding the innovative science that will deliver a cure. Our	

		mission is to bring about the first life-changing dementia treatment by 2025. Our vision is a world where people are free from the fear, harm and heartbreak of dementia.
Overall		We agree with the overall methodology for this review, and the overall conclusion that it is not currently appropriate to implement a national screening programme for dementia. In terms of the appraisal of each criterion, we would support the individual conclusions reached by the review.
Association between MCI and dementia		We agree that the relationship between MCI and the development of one of the underlying diseases that cause dementia is not currently clear. We support the recommendation that more research is needed in this area to ensure consistent definitions, methodology and reporting approaches. We also need more research to better understand the epidemiology and natural history of both dementia and mild cognitive impairment.
Accuracy of screening tools		We agree that there is currently a gap between the analytical and clinical utility of the biomarker and imaging techniques, which needs to be addressed in order to offer an accurate and consistent screening technique.
Acceptability of screening		We note that there is limited evidence to provide specific insight into the acceptability of screening for dementia. We would encourage further research in this area specifically in the UK – often perceptions are highly localised to individual countries and therefore it may not be appropriate to utilise studies from other countries.

2. Alzheimer's Society

Name:	Jo Baxter	Email address:	XXXX XXXX
Organisation (if appropriate):	Alzheimer's Society		
Role:	Policy Officer		
<p>Do you consent to your name being published on the UK NSC website alongside your response?</p> <p style="text-align: center;">Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p>			
Section and / or page number	Text or issue to which comments relate	Comment	
		<i>Please use a new row for each comment and add extra rows as required.</i>	
Page 6	'The UK NSC still cannot recommend population screening for dementia in adults. There is not enough new evidence to change the conclusions of the previous UK NSC reviews'	We agree with the recommendation of the review, that there is not enough evidence to recommend screening for dementia.	
Page 17	'This is because while MCI could represent a potential early symptomatic stage of the condition it could also represent a significant source of over-diagnosis.'	The reference to 'over-diagnosis' here is unclear. MCI identifies people at greater risk of dementia, and whilst some people identified as having MCI will develop dementia, others will not, it would be fair to assume that a health professional would communicate this message on risk to patients. There would be no 'over-diagnosis' of dementia, as dementia is not being diagnosed.	
Table 7	Inclusion criteria	It may be useful for the review to provide further summaries of	

Page 21-23		evidence from studies that, although not meeting the eligibility criteria for inclusion in full, still provide useful evidence – for example studies not based on a screen detected population.
Page 35	Accuracy of screening tools	<p>It would be useful for the review of these cognitive assessment tools to be placed in the context of current practice of diagnosis of dementia, and its complexity.</p> <p>The NICE guideline for dementia recommends that a cognitive test forms one part of initial assessment, along with taking a history (including cognitive, behavioural and psychological symptoms, and the impact of symptoms on daily life), a physical examination, and appropriate blood and urine tests, prior to referral to a specialist diagnostic service.</p>
Page 58	‘The current recommendation not to introduce a UK systematic population screening programme for dementia should be retained.’	Looking to future reviews, it is important to consider that there has been an increasing research focus on exploring potential disease-modifying treatments for asymptomatic stages of Alzheimer’s disease (characterised by biomarkers or pathology of Alzheimer’s disease without signs or symptoms), that would delay or stop cognitive decline. It is important to consider the implications of any developments in this area on reviewing the case for screening for dementia.

3. Association of British Neurologists Cognitive Advisory Group

Name:	Jeremy Brown	Email address:	xxxx xxxx
Organisation (if appropriate):	Association of British Neurologists (ABN)		
Role:	ABN Cognitive Advisory Group Chair		
<p>Do you consent to your name being published on the UK NSC website alongside your response?</p> <p style="text-align: center;">Yes <input checked="" type="checkbox"/> No <input type="checkbox"/></p>			
Section and / or page number	Text or issue to which comments relate	Comment	
		<p><i>Please use a new row for each comment and add extra rows as required.</i></p> <p>This is a long document and we have had limited time to study it in detail. All members of the group who have commented agree that we should endorse the NSC decision not to recommend population screening for dementia or MCI. The review is of high quality and thorough.</p>	

4. British Geriatric Society

Name:	XXXX XXXX	Email address:	XXXX XXXX
Organisation (if appropriate):	British Geriatrics Society		
Role:	XXXX XXXX		
<p>Do you consent to your name being published on the UK NSC website alongside your response?</p> <p style="text-align: center;">Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p>			
Section and / or page number	Text or issue to which comments relate	Comment	
		<i>Please use a new row for each comment and add extra rows as required.</i>	
All pages	All	The review of the evidence is fair and we have no concerns about their conclusion that screening should not be instituted.	



5. Royal College of Physicians

The following response was submitted directly via email to the Evidence team:

Dear all

The RCP is grateful for the opportunity to respond to the above consultation.

We would like to endorse the response submitted by the British Geriatric Society (BGS).

I would be grateful if you could confirm receipt.

Best wishes

xxxx xxxx



6. Two members of staff at University Hospitals of Leicester NHS Trust

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

Yes

No

As discussed, I have read the recommendations and it states that “The current recommendation not to introduce a UK systematic population screening programme for dementia should be retained.” My response/comment would be that all Acute NHS Organisations are mandated under the NHS Standard Contract to complete the FAIR dementia screening tool and complete a data return, on this basis there is partial screening of acutely unwell patients in place. The expectation is that this cost burden is included in tariff for providers. Any changes to the recommendations on the screening protocol should consider how these will be funded in the NHS and how this monies will flow to providers.

Kind regards

xxxx xxxx

As I understand it this is Public Health England’s recommendation that a screening programme to screen all over 65’s for dementia is not beneficial. The inpatient screening of over 65’s was previously a CQUIN and so we had to report the numbers. We do still screen over 65’s and, as I understand it, there is bi-annual reporting to the QAC. Informatics send information to patient experience and xxxx xxxx validates this and the renal team does the same.

Our screening is by asking if there have been concerns with memory and then proceeding with the AMT if appropriate. I agree that widespread population screening of over 65’s is inappropriate but I think it is important to be aware of cognitive impairment and using the inpatient setting to potentially highlight concerns, especially in the older population group is important.

Best Wishes

xxxx xxxx