PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	Proactive approaches to identifying dementia and dementia risk; a qualitative study of public attitudes and preferences
AUTHORS	Robinson, Louise; Dickinson, Claire; Magklara, Eleni; Newton, Lisa; Prato, Laura; Bamford, Claire

VERSION 1 – REVIEW

REVIEWER	Peter Whitehouse Case Western Reserve University USA University of Toronto Canada None except author of book The Myth of Alzheimer's disease and other critical articles and essays
REVIEW RETURNED	19-Aug-2017

GENERAL COMMENTS	Rather remarkably, the article appears to be based around some misconceptions about dementia. In the early pages they discuss that dementia is associated with aging populations. Yes dementia is more common in older people but it can occur at any age. To even mention the idea that there is no cure yet for dementia on page 3 implies that dementia is a singular condition that can be cured. Clearly the dementias as a group are not. Even talking about curing specific dementias like Alzheimers as the authors point out later is becoming problematic. Talking about cure in any way biases the conversation towards a medical framework. It would have been helpful to get details on the information presented to the participants before the discussion started,. The discussion of the limited understanding of dementia on the part of the participants is interesting because experts have all the same limtiations. Trajectories are often unpredictable. The boundaries between age-related memory decline, mild cognitive impairment, and dementia are fuzzy. Experts themselves are often inconsistent in describing the relationships between Alzheimer's and dementia. Most people now do not believe Alzheimer's is a single condition so why are they using the singular noun there. Moreover, most older people have mixed pathologies. In other words this article is using a framework to try to fathom laypersons attitudes that has largely proven to be confusing and relatively poorly reliable and validated even amongst experts. No wonder they find out that laypeople are confused.

	In discussion on page 5 lines 40s making sense of proactive approaches I don't find the criticisms of the participants particularly surprising. Case finding of people with mild cognitive impairment might in fact affect prevalence of dementia . And how is identifying people with known risk factors different than at least contributing to the knowledge about who is going to develop dementia (box 2) Genetic testing can be confusing to even experts. It is not surprising that laypeople do not understand the difference between deterministic and susceptibility loci. Experts are confused about the relationship between early onset and late onset Alzheimer's forms. Are they the same or different? Information from susceptibility loci like ApoE are particularly difficult to interpret as risks may vary as a function of other health conditions and ethnic identification and the gene itself is pleiotropic. With regards to attitudes towards proactive approaches I would similarly see variation in the opinion of experts. Most these days would agree that controlling vascular risk factors and physical exercise are important. But uncertainty about the role of these factors and others particularly in individuals is huge I am a bit confused about what they considered proactive approaches to be. Are they speaking about amyloid vaccination or public health interventions? Why would they say that people question the value of proactive approaches for a condition for which no cure was available? Even if you cannot cure you can try to prevent or delay. With regards to practical issues the authors should discuss more about the problems of labels. In the discussion once again what is meant by early diagnosis and of what ? Was the expression timely diagnosis evident in the conversations. Are we diagnosing mild cognitive impairment? The ideas expressed in the conclusion deserve more critical analysis. The idea of a vascular disease risk assessment in primary care makes some sense but would this not be similar to the risk for dementia assessment tool with notable exceptions like past history of head injury. Are there participants correct in assessing that we should be focusing on risk for dementia as brain health in the context of overall health? Was there any discussion of whether we should consider that everybody is at risk for dementia as we get older and that the personalized aspects of this risk do exist but in general everyone should eat a better diet exercise keep cognitively and socially engaged to prevent dementia as well as other age-related health conditions.

REVIEWER	Dr Carole Parsons School of Pharmacy Queen's University Belfast Northern Ireland, UK
REVIEW RETURNED	25-Sep-2017

GENERAL COMMENTS	This manuscript describes a qualitative study examining public attitudes and preferences towards identifying dementia and dementia risk. It is well-written, with detailed explanation of the methods of data collection and analysis, and reported using the

	COREQ guidelines. The discussion supports the findings, places them in the context of the available literature and includes future research priorities. In my opinion, subject to addressing a few minor typographical errors, this manuscript is suitable for publication by BMJ Open.

REVIEWER	Constance Dimity Pond University of Newcastle, Australia I have been part of a team running a "community jury" approach to identifying consumer approaches to dementia.
REVIEW RETURNED	24-Oct-2017

GENERAL COMMENTS	This is an important and interesting paper. My one comment is that clearly participants had difficulty distinguishing proactive approaches to dementia diagnosis and to identification of people at high risk of dementia. The authors make this clear in their presentation of the results. However, it is not clear in the abstract, which only mentions that participants were positive about proactive approaches to early identification. In the abstract this is mentioned as preferably embedded in routine health assessments, whereas in the discussion it is proactive approach to risk of dementia (rather than early identification) that is referred to as preferably embedded in routine health assessments. The authors should amend the manuscript to distinguish between these concepts, even though participants clearly had difficulty in doing so.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

▪ Rather remarkably, the article appears to be based around some misconceptions about dementia. In the early pages they discuss that dementia is associated with aging populations. Yes dementia is more common in older people but it can occur at any age.

Response: We apologise to Reviewer 1 as we did not intend to intentionally mislead the reader. Notwithstanding we have carefully reviewed our text and clarify that nowhere in the ‘early pages’ do we state that dementia only occurs in older people. We comment on the ‘changes in incidence and prevalence seen recently in western societies with rapidly ageing populations’ and appropriately reference this to current evidence from cohort studies.

▪ It would have been helpful to get details on the information presented to the participants before the discussion started.

Response:We apologise to for providing insufficient detail on this aspect; additional text has been added to BOX 1, p 15.

▪ The discussion of the limited understanding of dementia on the part of the participants is interesting because experts have all the same limitations… The boundaries between age-related memory decline, mild cognitive impairment, and dementia are fuzzy. Experts themselves are often inconsistent in describing the relationships between Alzheimer’s and dementia.

▪ In discussion on page 5 lines 40s making sense of proactive approaches I don’t find the criticisms of the participants particularly surprising. ….With regards to attitudes towards proactive approaches I would similarly see variation in the opinion of experts.

Response: We thank Reviewer 1 for highlighting the obvious issue of continuing confusion amongst dementia experts about both the issues of:
i) Age-related memory decline, mild cognitive impairment and dementia and
ii) Pro-active approaches to earlier detection of dementia and those at high risk.
In hindsight we should have commented on this in our discussion section; appropriate text has been inserted at the start of paragraph two in the discussion section and referenced accordingly (page 9). The confusion amongst our public participants around dementia as a condition, and approaches to its earlier identification, is unsurprising in an area where professionals often fail to achieve consensus (refs Petersen 2014; Tang 2015) and expert classifications change (Sachdev2014).

▪ With regards to practical issues the authors should discuss more about the problems of labels. In the discussion once again what is meant by early diagnosis and of what ? Was the expression timely diagnosis evident in the conversations. Are we diagnosing mild cognitive impairment?

Response: Reviewer 1 rightly signposts us to the complex issue of diagnostic labels in the field of dementia especially the lack of consistency globally around the use of MCI as a diagnostic label. We have added text on the challenges of diagnostic labelling to the second paragraph of the discussion. Notwithstanding one of the key challenges around introducing approaches to the earlier identification of people with dementia, and also those at higher risk, is a continuing professional stigma around using the diagnostic label of dementia and opening saying the D word to patients despite increasing public awareness campaigns (Robinson 2011). Variations in international clinical practice around the use of Mild Cognitive Impairment as a diagnostic label further increase professional inconsistencies (Whitehouse 2011).

▪ I am a bit confused about what they considered proactive approaches to be. Are they speaking about amyloid vaccination or public health interventions? Why would they say that people question the value of proactive approaches for a condition for which no cure was available? Even if you cannot cure you can try to prevent or delay.

Response: We apologise for this confusion; however we did state in the introduction to our paper what we meant by the proactive approaches to earlier detection of dementia as per the original text below: “Although general population screening for dementia is not currently advocated,9 identifying groups at high risk of developing dementia and giving tailored advice to reduce individual risk, has been recommended by the World Health Organisation 10 as a cost effective strategy to reduce the global burden of dementia.7 This policy shift has resulted in initiatives such as targeted case finding 11 12 opportunistic assessment to identity possible signs of dementia in a patient at high risk of developing dementia (e.g. those aged 75; older people with high vascular risk, learning disabilities and Parkinson’s disease 13 14).”

▪ Are there participants correct in assessing that we should be focusing on risk for dementia as brain health in the context of overall health? Was there any discussion of whether we should consider that everybody is at risk for dementia as we get older and that the personalized aspects of this risk do exist but in general everyone should eat a better diet exercise keep cognitively and socially engaged to prevent dementia as well as other age-related health conditions.

Response: As already clarified above, we did present detailed information to the participants about the key risk factors for dementia and highlighted the importance of age as the key risk factor for the more common dementias. They then drew up their own opinions as to how such risk should be measured in practice and concluded cognitive risk assessment should be conducted within the context of overall health.

VERSION 2 – REVIEW

REVIEWER	Peter Whitehouse Case Western Reserve University USA
REVIEW RETURNED	05-Nov-2017

GENERAL COMMENTS	The authors have made a very good response to the reviewer's input. I would request two actions where they did not fully response to my critique . First the authors are correct is saying they did not specifically exclude dementia as a condition occurring across the life-span in their text, but they referred to the association with aging populations several times. Hence it may be thought by readers that dementia is just associated with aging populations and hence the elderly . In an article about public attitudes about dementia being clear about this point I think is important. In a prevention conversation space which might affect resource allocation, life-course perspectives are critical in my view, lest we do not attend to the brain health of children adequately. With regards to their rebuttal that they did inform the participants about proactive factors I would still ask for some mention of whether amyloid/biologicals/pharmaceutical approaches were part of the discussion. There is huge energy to get people to enroll in trials where the implied message from researchers and pharmaceutical companies is that the greatest risk factor for not preventing/curing dementia is under investment in clinical trials. Even if this was never a topic the reader might ask whether this came up at all in the interviews. The authors have made a very good response to the reviewer's input. I would request two actions. First the authors are correct is saying they did not specifically exclude dementia as a condition occurring across the life-span, they referred to the association with aging populations

REVIEWER	Constance Dimity Pond University of Newcastle, Australia As declared previously on first review of this manuscript I have recently become a member of a special interest group in the elderly, along with the first author of this manuscript. We have yet to meet, however.
REVIEW RETURNED	20-Nov-2017

GENERAL COMMENTS	I believe the manuscript has been revised. I am happy with the version reviewed this time. I have not reviewed it in the light of the other reviewer's comments.

VERSION 2 – AUTHOR RESPONSE

Point 1: Dementia is not just an illness of old age but occurs across the life course
" The authors have made a very good response to the reviewer's input. I would request two actions where they did not fully response to my critique . First the authors are correct is saying they did not specifically exclude dementia as a condition occurring across the life-span in their text, but they referred to the association with aging populations several times. Hence it may be thought by readers that dementia is just associated with aging populations and hence the elderly . In an article about public attitudes about dementia being clear about this point I think is important. In a prevention conversation space which might affect resource allocation, life-course perspectives are critical in my view, lest we do not attend to the brain health of children adequately".

Response: We have amended our introduction to emphasise this important point with the first sentence now re-written, " Dementia has a huge impact on people living with the illness, and their families, and incurs substantial healthcare and societal costs; although more common in older populations, this impact may be greater when dementia occurs earlier in the life course and affects an individual's ability to work and care for their family." We have also removed the phrase 'ageing populations' from the introduction and where possible, reiterated the fact that although dementia is more common in older people, it can also present earlier in the life course (see results section, page 7).

Point 2: Proactive approaches discussed with participants
"With regards to their rebuttal that they did inform the participants about proactive factors I would still ask for some mention of whether amyloid/biologicals/pharmaceutical approaches were part of the discussion. There is huge energy to get people to enroll in trials where the implied message from researchers and pharmaceutical companies is that the greatest risk factor for not preventing/curing dementia is under investment in clinical trials. Even if this was never a topic the reader might ask whether this came up at all in the interviews."

Response: As this was a challenging area to present succinctly and in lay terms to our public participants, we did not use the term amyloid or amyloid related treatment options but did provide them with a brief summary about genetic factors and genetic screening and also the potential of future research to develop new drugs/vaccines to prevent or delay onset of dementia. Additional text has been added to Box 1.

VERSION 3 – REVIEW

REVIEWER	Peter Whitehouse Case Western Reserve University
REVIEW RETURNED	03-Dec-2017

GENERAL COMMENTS	Thanks for responding to the two issues raised in my second review. I am not sure it is best to refer to young people with leaning disabilities as having a dementia. Young people with meningitis or head injury can have a dementia and there are many other causes. You could pick a better example than learning disabilties. Also it is perfectly fine to focus in this paper on proactive approaches in adults and elders without considering children but the problem for me was an implication in the earlier version of the paper that only adults and elders were at risk for dementia

VERSION 3 – AUTHOR RESPONSE

Reviewer 1 does not consider Learning disabilities to be a good choice as an example of younger adults who can develop dementia; we find this strange as adults with learning disabilities e.g. those with Downs syndrome are at high risk of developing cognitive impairment and dementia at a younger age; he suggests head injury.
We have amended the relevant sentence in the introduction to now better reflect, we hope, that dementia can develop at any point across the adult life course, albeit being much more common after the age of 75years, from younger adults (post head injury, Downs), middle age (high vascular risk) to older people with predisposing conditions such as Parkinsons.

VERSION 4 – REVIEW

REVIEWER	Peter Whitehouse Case, USA
REVIEW RETURNED	13-Dec-2017

GENERAL COMMENTS	This reviewer was concerned that a blanket statement about children with learning disabilities and the implied need for ongoing screening would raise unnecessary concerns about the broad class of children labeled with learning disabilities. Certainly Down's is one for of cognitive disability which might better be labeled a developmental disability. And certainly they are at specific risk for later dementia. This might even be a UK versus US distinction in language as to what is considered a learning disability. That said this is not my area and as before i will recommend acceptance (again) .