



Public Health
England

Dementia

Workshop series to support prioritisation
of research

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through advocacy, partnerships, world-class science, knowledge and intelligence, and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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Published: August 2015

PHE publications gateway number: 2015222



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Summary of the main research priorities identified

The following are the key research priorities identified during the discussion:

- production/synthesis of deep population level data to allow policy makers to report to ministers would be useful, giving clear information about issues such as the age at which people develop dementia and the age at which formal support starts
- further efforts to learn from international comparisons rather than replicating existing research, particularly across Europe, particularly where UK data are missing or difficult to obtain
- additional research and data collection on:
 - working-age dementia
 - brain injury as risk factor for dementia
 - alcohol as risk factor for dementia
 - depression as risk factor for dementia
- targeted research to collect data on dementia in ethnic minorities, for example whether assessment tools are appropriate and validated in minority populations
- additional data on regular assessments and monitoring of disease progression, including contact with care services and hospitals etc. could be very informative for understanding prognosis
- examine potential barriers to implementation, looking at what changes or interventions are acceptable to people, what is most effective and what is most listened to
- determination of the relative effect of reduction of different risk factors including:
 - what are the most important elements of possible interventions?
 - what is the most cost effective way to implement a series of interventions within a given situation?
- methodological development to determine appropriate intermediate measures of success of dementia prevention interventions across different stages and populations
- how best to create conditions to live well with dementia in the community?
- describe the societal characteristics necessary to optimise wrap-around support for people with dementia and use as a basis to determine the changes required within current environments
- what happens to people after they are diagnosed, particularly with early diagnosis?
- what symptoms and types of dementia respond to what interventions and at what stage(s)?
- synthesis of what we already know about prevention that will enable more people to live well

- what constitutes useful and effective support and treatment for the 'oldest old'?
- work with ethics committees/COREC to improve guidance on including dementia patients in studies and trials
- research on the effectiveness of rehabilitation interventions such as increased exercise for dementia patients
- additional research studies on dementia utilising populations within care homes in order to improve their quality of life and care
- further research and evaluation to determine the language around dementia prevention vs healthy behaviour and lifestyle that is most helpful to different population groups

Key overarching issues

Definition - framework

The term 'dementia' is used to cover a range of pathologies including mild cognitive impairment (MCI), Alzheimer's disease, and vascular dementias. For the purposes of this discussion, participants agreed to consider the overall dementia syndrome and the process of people reaching frailty in terms of their brain function.

The current political and social interest in dementia is creating unprecedented opportunities for action. For public health, the objective of research was considered to be an evidence-based approach to delay as far as possible the onset and progression of dementia, aligning it as closely as possible to terminal decline and death, thereby ensuring that people live well for longer.

The recent research prioritisation exercise carried out by the James Lind Alliance and led by the Alzheimer's Society was highlighted and provides a comprehensive list of research priorities from patient and carer perspectives and other stakeholders.¹

Funding and capacity

A requirement for inclusion of measures of cognitive outcome in all future research studies would enable additional data collection and prevent unnecessary duplication of research.

When researching dementia, it was agreed to be vital for all studies to make clear what definition/s with respect to cognitive decline and dementia are used to allow data to be compared across multiple studies.

It is also important to note that dementia can be related to other health conditions and to consider the impact of multimorbidity, where people may have a number of

¹ http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1804

conditions each with a differing impact on their health and wellbeing. Risk factors for dementia are often also related to other conditions and so a joined up approach to disease prevention is required.

The current funding landscape is better suited to research where results can be measured over a short time period but the value of long-term investments must not be underestimated. More thought should be put into succession planning and funding for maintenance of core structures, such as longitudinal studies, for future use.

Gaps in research capacity were identified as a significant problem, particularly at the intermediate researcher level. Participants urged funders and PHE to think collectively about capacity building in the fields relevant to public health to ensure a sustainable model for future academic research and for academic and service linkage, thinking about the types of training necessary, joint posts etc., and building on existing capacity initiatives.

Stratification

An important issue across all disease areas emerging particularly from pharmaceutical trials is the need to take a stratified approach to patient treatment and care – an approach which subdivides patients into groups based on their risk of developing specific diseases or their response to particular therapies. The ultimate aim of a stratified approach to medicine is to enable health and care professionals to provide the 'right treatment, for the right person, at the right time'. However, given that this approach often relies on using biological markers of disease to separate patients into specific groups for diagnosis and treatment, this is very difficult for dementia where the biological processes are not yet known. However, it does highlight the importance of population definition for data collection and testing of interventions.

Introduction and overview

During financial year 2014/15, PHE ran a series of four workshops, culminating in a series of five reports, on the topic areas below to specifically explore the research needs and evidence gaps for those topics:

- Obesity 9 September 2014
- Dementia 26 August 2014
- Best Start in Life 25 November 2014
- Cross-cutting themes (report only)
- Evaluation 11 February 2015

This is the report for the dementia; there is also a report detailing items that were discussed at more than one workshop. The aim of these workshops was to engage with the academic, policy, research funding and public health communities to explore research requirements in topic-specific, PHE priority areas. The discussion aimed to identify current major research challenges and gaps relevant to dementia. This addresses the 'public health research narrative' as proposed in the PHE Research, Development and Innovation strategy 'Doing, Supporting and Using Public Health Research'.

This is a summary report to reflect the views expressed at the workshop.

Intended audience for this report

The intended audience for this report includes all those involved in the research process for dementia related research including academics and other researchers, research councils, health research charities, other research funders and commissioners.

About the workshop

Among the 32 participants were senior members of many of the most prestigious national dementia-related academic research groups (see Annex 1 for full participant list). Their engagement with PHE priorities is an excellent indication of future potential collaboration.

The workshop was split into three sections:

1. Two short presentations giving an overview of PHE R&D strategy, PHE ambitions and structures, and a presentation by the PHE lead for preventable dementia
2. An open discussion and plenary
3. Group sessions where participants were split into four groups to address a set of specific questions related to dementia research needs

Findings

Discussion topic	Principal views expressed	Suggestions for future research
Using existing data better	<ul style="list-style-type: none"> Although there are some areas where additional baseline data would be helpful, making better use of data that has already been collected is key. Cognitive impairment has been measured in all the large UK longitudinal cohort studies and these data have not yet been fully exploited. Routine data from primary care could be better used to look at causative factors in dementia. Data from the Department of Work and Pensions, which recorded when benefits are claimed, could give information on levels of working age dementia, for example. This is an immense data resource which is entirely underexploited for research, although the difficulties in translating the data into a usable resource were acknowledged. A large mapping exercise under the EU Joint Programme on Neurodegenerative Disease Research (JPND) highlights dementia related data from UK and European population studies. The description of each cohort is available on the 	<ul style="list-style-type: none"> From the policy perspective, having deeper population level data on dementia to report to ministers would be useful, giving clear information about issues such as the age ranges at which people develop dementia and the age or stage at which formal support starts. These data might already exist but have not been brought together in this way and this would be very powerful. Further efforts should be made to learn from international comparisons rather than replicating existing research, particularly across Europe. This could be particularly useful in areas where data are missing or difficult to obtain.

	<p>JPND website for all to use.²</p> <ul style="list-style-type: none"> • The JPND strategy on natural experiment opportunities across Europe raises questions about how best to make that agenda available to researchers to allow them to conduct the research. Natural experiments can be difficult given the disconnect between health and public health services in studies across different implementation environments, and it would be helpful to create structures to facilitate this kind of research. 	<p>However, the difficulties in translating results meaningfully across different health and social care systems were acknowledged.</p>
Data gaps	<ul style="list-style-type: none"> • Additional baseline data on working age dementia and the effects of toxic factors like brain injury or alcohol are required. • A large volume of data exists covering aetiological risk factors and risk of dementia. However, data around prognosis is less available. • Better data is required on dementia in ethnic minorities, recognising that this is a diverse category and the largest growing population is those with mixed ethnicity. These groups must be considered individually, not as a single entity, along with generational differences and geographical differences, such as ethnic 'minorities' actually being the majority in some communities. The cultural construction of health and community behaviour and experience is different in the different groups, leading to different needs and approaches. The lack of research evidence on dementia in ethnic minorities has also been highlighted in the JPND mapping exercise. A targeted approach will be required to increase research in minority groups. • Other smaller groups need to be considered separately 	<ul style="list-style-type: none"> • Additional research and data collection on: <ul style="list-style-type: none"> ○ working-age dementia. ○ brain injury as risk factor for dementia ○ alcohol as risk factor for dementia. ○ depression as risk factor for dementia. • Targeted research to collect data on dementia in ethnic minorities, for example whether screening tools are appropriate and validated in minority populations. • Additional data on regular assessments and monitoring of disease progression, including contact with care services and hospitals etc. could be very informative for understanding prognosis.

² <http://www.neurodegenerationresearch.eu/initiatives/mapping-exercise/>

	<p>including dementia in those with learning disabilities or neurological conditions.</p> <ul style="list-style-type: none"> • Research has identified and examined a number of risk factors for dementia, many of which are also risk factors for other diseases. However, less is known about how risk factors interact. One risk factor where additional research was required is depression, where it was unclear whether data was being collected and well used. It is currently not known whether early identification and prevention/treatment of depression could be protective for dementia. 	
What works to benefit dementia patients?	<ul style="list-style-type: none"> • A single solution to tackling dementia will not be possible. A series of interventions is required, with different elements for different situations. • Implementation studies from the existing body of evidence are needed to provide evidence demonstrating what works to prevent and delay dementia. • Positive interventions that could be implemented immediately to deliver a range of benefits for older people (possibly with a reduction in the risk of dementia) include: increasing computer use amongst older people; improving hearing testing; and correcting hearing loss at an earlier age. • The long timescales involved with testing interventions in dementia prevention makes evaluation of success challenging. Evidence for positive outcomes, particularly from early interventions, would fall a long way outside normal funding timeframes. Research frameworks should allow for interventions with long-term anticipated outcomes. • Electronic communications and social media may open up new possibilities for longer-term follow up. UK Biobank is carrying out regular follow up with a group of participants which may 	<ul style="list-style-type: none"> • Examine potential barriers to implementation, looking at what changes or interventions are acceptable to people, what is most effective and what is most listened to. • Research priorities to determine the relative effect of reduction of different risk factors should cover: <ul style="list-style-type: none"> ○ What are the most important elements of possible interventions? ○ What is the most cost effective way to implement a series of interventions within a given situation? • Methodological development to determine appropriate intermediate measures of success of dementia prevention interventions. Mild and borderline cognitive decline in

	lead to further methodological developments in this area.	particular are difficult to measure consistently and measurement tools may operate differently in different populations.
Focus resources effectively	<ul style="list-style-type: none"> • As well as primary, secondary and tertiary prevention, public health includes the rational use of (health and care) resources. With constrained finances, it is important to optimise our limited resources and avoid wasting funds on initiatives that are not validated and non-evidence based. • There are examples of 'myth and legend' around dementia risk reduction e.g. optimism over the power of brain training, when the evidence is unclear how effective this is and at what stage of cognitive decline. 	
Construct dementia-friendly	<ul style="list-style-type: none"> • The importance of the social construction of dementia and reduction of disabling environments and communities was 	<ul style="list-style-type: none"> • Further research is required to determine how best to create

environments	<p>highlighted.</p> <ul style="list-style-type: none"> • The empowerment and inclusion of people with dementia in design and creation of dementia friendly communities and in the delivery of care is important, as is the need for locally derived solutions. • Work on healthy cities and age-friendly environments must include dementia as it is not practicable or desirable to carry out separate initiatives. • A number of 'healthy city/neighbourhood' type research sites have been established, most of which have been led by the research community. It would be interesting to initiate a study with genuine coproduction, driven by a community prepared to embrace a whole town/city approach and willing to work with researchers to evaluate interventions. PHE may be able to play a key role in establishing this type of mass-participation approach. It would be important to involve an entire community to prevent worsening inequalities. 	<p>conditions to live well with dementia in the community.</p> <ul style="list-style-type: none"> • Describe the societal characteristics necessary to optimise wrap-around support for people with cognitive difficulty and use this as a basis to determine the changes required within their current environment.
Effective diagnosis	<ul style="list-style-type: none"> • Both over and under-diagnosis in dementia occur within different groups. • It was important to focus on the benefits of a diagnosis of dementia for the person in their lifetime, not simply when the pathology is detectable. • Once it is known which people may respond to intervention/treatment and at what thresholds, then diagnosis could be targeted in order to be timely and give patients the best advantage. 	<ul style="list-style-type: none"> • Research is required to understand what happens to people after they are diagnosed, particularly with early diagnosis. • Research is needed on what types of dementia respond to what interventions and at what stage(s), as well as synthesis of what we already know about prevention that will enable people to live well.
Care for people with	<ul style="list-style-type: none"> • Given the levels of multimorbidity in old age, what are the merits of focusing on diagnosis and management of one disease at a time? 	<ul style="list-style-type: none"> • Further research is required on what constitutes useful and appropriate support and treatment for the 'oldest

multimorbidity	<ul style="list-style-type: none"> There is not enough evidence currently on the best medical management of octogenarians and other older people. Many clinical decisions are currently based on evidence from clinical trials carried out on much younger age groups. The NIHR School for Public Health Research's Ageing Well programme uses routine data, particularly primary care databases, to examine whether there are differences in effect sizes of drugs within the older population, compared to younger people, which should contribute to this knowledge gap. 	old'.
Obesity and dementia	<ul style="list-style-type: none"> Significant overlap exists between risk factors for obesity and those for dementia (and other conditions), such as low levels of physical activity. Obesity itself is known to be a risk factor for dementia. Obesity is currently rising fastest in the peri-retirement group but attention is often focused on childhood obesity. Current trends suggest large increases in obesity alongside cognitive ageing, as well as musculoskeletal and cardiovascular problems, within a relatively short time period. Some obesity research suggests the answers to the problem of obesity lie in the structure of society and environment and food supply, and there was discussion of possible areas for effective legislation such as tax on sugar, controls on added fat and/or sugar in processed food, alterations in farming subsidies to encourage production of healthy foods. Participants suggested that a focus on dementia might be useful to encourage further thinking about healthier diets / lifestyles. 	
Building approaches to rehabilitation in	<ul style="list-style-type: none"> There is a perception that people with dementia will not benefit from rehabilitation for comorbid conditions so this area of research is underexploited. 	<ul style="list-style-type: none"> Work with ethics committees/COREC to improve guidance on including dementia patients in studies and trials.

dementia	<ul style="list-style-type: none"> • There is no existing general rehabilitation programme following an early diagnosis of dementia, in contrast to programmes for people who have had a heart attack or stroke, for example. Rehabilitation interventions such as increased exercise could be helpful. If it is found that rehabilitation programmes increase quality of life of people with dementia and/or carers then this may be relatively straightforward to implement within current healthcare frameworks. • The lack of research evidence in this area may also be due to the exclusion of some patients with dementia from rehabilitation studies and other trials. Inclusion of people with dementia can be difficult but this should not be sufficient reason to exclude them. Engagement with ethics committees and other bodies may be necessary to develop better guidance on the inclusion of people with cognitive difficulties where possible. 	<ul style="list-style-type: none"> • Research on the effectiveness of rehabilitation interventions such as increased exercise for dementia patients.
Carers and care homes	<ul style="list-style-type: none"> • Carers provide the majority of care in dementia, in contrast to many medical conditions where care is predominantly clinically based. Participants agreed that the UK is a leading centre of research on carers and a large body of descriptive work already exists or is underway. There is now a need to make better use of the existing research evidence and implement what has been demonstrated to work. • Care homes are a useful and currently underexploited setting for dementia research. 	<ul style="list-style-type: none"> • Additional research studies on residents with dementia within care homes.
Use of Language	<ul style="list-style-type: none"> • Evidence from workshops and focus groups suggests that models focusing on dementia and healthy behaviours and lifestyles are differently effective with different sections of the population. Further research and evaluation are needed to determine the language that is most helpful to different 	<ul style="list-style-type: none"> • Further research and evaluation to determine the language around dementia prevention vs healthy behaviour and lifestyle that is most helpful to different population groups.

	population groups although some work in this area is underway.	
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Additional points

There are currently no standards for technologies for people with dementia so no indication they have been evaluated or demonstrated to work. Some kind of quality marking for properly evaluated innovations might be useful and worth exploring.

PHE co-producing research with local authorities can be an important source of evidence. Mapping at the local authority level of inclusion of dementia in Joint Strategic Needs Assessments (JSNA) and existing successful and unsuccessful interventions in dementia prevention and care would allow areas to compare what works well and encourage improvement in areas of need. PHE could have an important role in highlighting inequalities and encouraging improvement locally, linking to data held by the Knowledge and Intelligence Teams and dementia network.

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