

## **A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025**

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# A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025

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**Objective:** National and global dementia plans have focused on the research ambition to develop a cure or disease-modifying therapy by 2025, with the initial focus on investment in drug discovery approaches. We set out to develop complementary research ambitions in the areas of prevention, diagnosis, intervention, and care and strategies for achieving them.

**Methods:** Alzheimer's Society facilitated a taskforce of leading UK clinicians and researchers in dementia, UK funders of dementia research, people with dementia, and carer representatives to develop, using iterative consensus methodology, goals and recommendations to advance dementia research.

**Results:** The taskforce developed 5 goals and 30 recommendations. The goals focused on preventing future cases of dementia through risk reduction, maximising the benefit of a dementia diagnosis, improving quality of life, enabling the dementia workforce to improve practice, and optimising the quality and inclusivity of health and social care systems. Recommendations addressed gaps in knowledge and limitations in research methodology or infrastructure that would facilitate research in prioritised areas. A 10-point action plan provides strategies for delivering the proposed research agenda.

**Conclusions:** By creating complementary goals for research that mirror the need to find effective treatments, we provide a framework that enables a focus for new investment and initiatives. This will support a broader and more holistic approach to research on dementia, addressing prevention, surveillance of population changes in risk and expression of dementia, the diagnostic process, diagnosis itself, interventions, social support, and care for people with dementia and their families.

## KEYWORDS

care, dementia research policy, prevention, research funding, risk reduction, social and applied science, 2025 goals for dementia

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## 1 | INTRODUCTION

By 2018, it is estimated that there will be 50 million people living with dementia globally, with an economic cost of \$1 trillion.<sup>1</sup> In response, the last decade has seen the development of multiple national and regional initiatives that seek to improve awareness, diagnosis, and care for people with dementia and their family carers. These plans have also identified the need for research to generate new ways of addressing the human, economic, and social costs of dementia for current and future generations.

A global response to dementia was initiated by the G7 countries during a summit held in 2013. G7 government leaders collectively called for innovation to improve the quality of life of people with dementia and their carers, and to develop a coordinated international action plan on research. The summit set the ambition to identify a cure or disease-modifying therapy for dementia by 2025 and to significantly increase the amount of global funding for research to reach that goal. There has followed a global increase in research funding for dementia. For example, a global Dementia Discovery Fund with an initial budget of \$100 million was created, and the United Kingdom has created a Dementia Research Institute with a predominant focus on understanding biological mechanisms of the disease. In the United States, the National Alzheimer's Project Act sets out detailed goals, milestones, and funding required to achieve the 2025 treatment ambition, and its National Institutes of Health budget for Alzheimer and related dementias has increased from \$504 million in 2013 to \$1.4 billion in 2017 to enable this.<sup>2</sup>

An unintended consequence of setting this ambitious "cure" research target is that the allocation of dementia research funding has increased in basic and applied biomedical research but grown far less in other areas. The International Alzheimer's Disease Research Portfolio was set up by the National Institute on Aging to compile a global database of dementia research funding.<sup>3</sup> Although not a complete dataset of every research project underway, of the 5837 dementia-related projects logged between 2014 and 2016, less than 1 in 20 (4.8%) was classified as epidemiology and even less, 3.2%, as care, support, and health economics.<sup>4</sup>

Initiatives in policy have started to address the need for a greater focus on a broader societal, public health perspective. This includes the need for much stronger evidence on which to base policy and practice for care and support of people affected by dementia. In May 2017, Member States of the World Health Organisation (WHO) endorsed a global action plan on the public health response to dementia and committed themselves to developing ambitious national strategies and implementation plans.<sup>5</sup> The global action plan calls on WHO Member States to develop, implement, and monitor the realisation of a national research agenda on prevention, diagnosis, treatment, and care of people with dementia in collaboration with academic and research institutions.

To guide future research in the United Kingdom and more widely, the Alzheimer's Society convened a taskforce to develop research goals in dementia prevention, diagnosis, intervention, and care. Alongside this activity, the group also developed an action plan to provide strategies to facilitate the recommendations being achieved. Together, these form a research road map to accelerate understanding by 2025.

### Key points

- A broad-based taskforce of researchers, clinicians, UK funders of dementia research, people with dementia, and carer representatives was convened to generate consensus on research ambitions in prevention, diagnosis, intervention, and care for people with dementia.
- Five goals and 30 recommendations that align with current national dementia strategies and plans were produced. A 10-point action plan was developed to support the delivery of these goals.
- This work is complementary to the global ambition to find a cure or disease-modifying treatment for dementia by 2025, which has helped set a clear research agenda for biomedical research. An equally strong and evidenced focus on prevention, diagnosis, intervention, and care is also vital for our ageing societies.

This sought to build on previous initiatives to identify gaps in dementia research, including the James Lind Alliance Priority Setting initiatives in the United Kingdom<sup>6</sup> and the WHO research priorities to reduce the global burden of dementia by 2025.<sup>7</sup> In the current exercise, challenges and barriers that can prevent the commissioning and delivery of research were also considered, so that the road map includes infrastructure, research, and methodological development needed to underpin the research priorities identified.

The research road map is intended for researchers who can respond through development of their own research proposals, and for funders and research policy stakeholders who can influence the availability and direction of research funding and the research environment, including strengthening and developing the United Kingdom's skill base with new capacity building.

## 2 | METHODS

The Alzheimer's Society convened a taskforce composed of researchers, clinicians, research funding agencies, and other relevant stakeholders. These were purposively focused to include a range of relevant disciplines, and to be leaders and emerging leaders in their fields. The disciplines covered by the group included health economics (A.C. H. and M.K.), gerontology and psychology (B.W., G.W., L.Cl., L.Co., and N.M.), occupational therapy (S.D.), primary care (L.R.), psychiatry (C.Ba., G.L., and S.B.), psychology, public health (C.Br. and L.L.), social care (J.Ma. and J.Mo.) (some were overlapping and included others such as nursing) as well as research funders (C.W., K.G., J.P.O., and C.v.L.) and lived experience (C.Bi.).

The taskforce met in January 2017 to conceptualise the research road map and goals and then participated in five iterative goal-specific teleconferences to develop recommendations. The taskforce met again in April 2017 to review and revise the first version of the road

map. Specific road map goals and recommendations were developed through additional group discussions. Each workgroup member also provided input through one-on-one interviews and in written comments on iterative drafts of the recommendations. Throughout the development of the recommendations, the group also identified challenges to their delivery, which formed the basis of a workshop to develop an action plan.

An online survey inviting feedback on goals and recommendations was distributed widely during June 2017 and completed by 60 participants who were mostly researchers with health and social care expertise as well as lay people affected by dementia, including people living with dementia and family carers. The taskforce met for the last time in August 2017 to refine the final road map incorporating consultation responses.

An action plan to support the road map was developed in parallel, through a half-day workshop in August 2017 with members of the taskforce, additional stakeholders from research and policy, and representatives of people affected by dementia invited from the Alzheimer's Society Research Network ( $n = 8$ ). At the workshop, participants worked in small groups to discuss the challenges of delivering the recommendations and developed possible solutions to overcome them.

Public and patient involvement in the process was guided by a former carer and lay member of the Alzheimer's Society Research Network, who took part in all stages of the process. The Alzheimer's Society consulted on the first draft of the road map with lay members of the Alzheimer's Society Research Network ( $n = 15$ ) and at a workshop at the Alzheimer's Society Annual Conference in May 2017 ( $n = 40$ ). People affected by dementia also responded to the online consultation.

## 3 | RESULTS

### 3.1 | Conceptualisation and scope of the research road map

The road map was created from the viewpoint of considering real-world outcomes for people affected by and at risk of dementia, to establish what works most effectively in different situations. In other words, to focus on the capabilities and behaviours of people affected by dementia and the symptoms and consequences of the disease to understand how to achieve the best outcomes possible. It was also influenced by ambitions that are common in national dementia policies, for instance, the ambitions to "live well/live better" with dementia and access to personalised services and to develop research recommendations that would allow evidence to be generated towards these ambitions. A core theme throughout the road map development was to address inequalities in access and outcomes between people affected by dementia. It was agreed that the purpose of the road map was not to set a pathway to discovering new pharmacological treatments and diagnostics, which has been covered elsewhere.<sup>8</sup> However, the road map includes recommendations for biomedical and pharmaceutical research where relevant to improving real-world outcomes.

The scope of the road map includes people currently living with a diagnosis of dementia, and also carers, families, friends, and other unpaid supporters, and wider groups such as local communities. This scope recognises that dementia impacts the individual's networks and that this impact is also societally important and requires a robust evidence base.

### 3.2 | Goals for research

Goals were developed through discussion and taskforce consensus, covering the scope of prevention, diagnosis, treatment, and care. Aspirational goals were framed to be explicit in the contribution that research could have in these areas, acknowledging that policy, training, awareness, commissioning, and education are also required.

The 5 prioritised goals are as follows:

1. Prevent future cases of dementia through increasing knowledge of risk and protective factors.
2. Maximise the benefits to people living with dementia and their families when seeking and receiving a diagnosis of dementia.
3. Improve quality of life for people affected by dementia, by promoting functional capabilities and independence, while preventing and treating negative consequences of dementia.
4. Enable the dementia workforce to improve practice and skills by increasing evidence to inform changes in practice and culture.
5. Optimise the quality and inclusivity of health and social care systems that support people affected by dementia.

### 3.3 | Recommendations for delivering the goals

For each of the 5 goals, recommendations for research were generated that would lead to advances in evidence that enable achievement of the goal. An important principle to emerge across all recommendations is that research should consider equity of access to reduce inequalities. The recommendations include both pharmacological and nonpharmacological interventions, where relevant, with the aim of establishing what is most effective for people affected by dementia. The recommendations for delivering each goal are presented in Tables 1–5.

### 3.4 | Setting a 2025 time frame

The taskforce debated whether it was realistic to set a time frame for each goal. Recognising the average length of research projects to be 3 to 5 years, it was agreed that significant advances in knowledge could be made in the 8 years before 2025, while accepting that translation into policy and practice might require additional time. These goals are presented as equivalent to the existing G7 ambition for new disease-modifying treatments.

### 3.5 | Actions to deliver the research goals and recommendations

Ambitious recommendations for research require significant increases in available funds to support research programmes. In addition to

**TABLE 1** Goal 1 and recommendations**Prevent Future Cases of Dementia Through Increasing Knowledge of Risk and Protective Factors**

1. Conduct epidemiological research to understand existing and identify novel risk and protective factors for developing dementia:
  - Collect robust surveillance data on new incidence and prevalence of dementia in the UK population.
  - Seek to better understand the causal reasons for recent changes in rates of dementia.
  - Conduct long-term studies that clarify the direction of causality.
  - Study populations that appear to be at lower, as well as increased, risk of developing dementia.
2. Develop life course models of dementia risk to inform points of intervention, including cost-effectiveness and strategies to reduce inequality. These should range from behaviours and environments at the individual level to modelling implications of nationally implemented policy.
3. Collect and combine biological, social, and environmental measures within epidemiological studies:
  - Increase brain donation from cohorts to correlate brain changes observed through investigating neuropathology with epidemiological findings.
  - Routinely link cohort data to health care records and patterns of service use.
4. Develop and test pragmatic, real-world-based interventions for known risk and protective factors for poor brain health:
  - Establish the intensity of interventions needed to modify risk of developing dementia, for individuals and groups with different baseline levels of risk.
  - Research the motivations for behaviour change in lifestyle factors relevant to risk of dementia at both individual and societal levels.
  - Establish and validate sensitive measures in healthy adults that predict delay in onset or prevention of dementia.
  - Use precision medicine (eg, genetics and phenotyping) approaches to define groups with similar risk profiles for intervention studies.
5. Evaluate different communication and messaging approaches for raising public awareness of risks for dementia, including alignment with other conditions that share risk factors such as heart disease and diabetes.

**TABLE 2** Goal 2 and recommendations**Maximise the Benefits to People Living With Dementia and Their Families of Seeking and Receiving a Diagnosis of Dementia**

1. Define what a "timely" and "quality" diagnosis of dementia means, recognising that this may need to be tailored to individual circumstances, to enable informed decision making.
2. Understand the reasons why people might voluntarily not wish to seek a diagnosis or attend appointments that could lead to a diagnosis, to identify the consequences and possible unmet needs for support and help.
3. Develop relevant pathways and outcome measures for a timely and quality diagnosis, against which diagnostic and support services can be assessed, supporting consistency across the United Kingdom:
  - Understand regional, demographic, socioeconomic differences in diagnosis rates and service usage and quality.
4. Research the most effective ways to communicate a diagnosis, including how recipients of a diagnosis understand the process and their role in decision making.
5. Evaluate and optimise models of postdiagnostic support provision, considering the outcomes and cost-effectiveness of these models.
6. Research the acceptability, cost-effectiveness and real-world outcomes of innovations in diagnostics, including noninvasive tests that support making a diagnosis in primary care, and tests in specialised memory services such as cerebrospinal fluid lumbar puncture and molecular positron emission tomography imaging.
7. Develop and evaluate interventions and support for people who, following a diagnostic process, are identified as having cognitive impairment (subjective or objective) but not dementia.

funding, there are opportunities to develop the infrastructure and resources available for research and to overcome barriers that inhibit the delivery and efficiency of research. The taskforce identified 10 areas for action that would enable research to be delivered against the recommendations. These areas would benefit from targeted initiatives or development of new resources.

1. Increasing funding available for research

The UK 2020 Challenge on Dementia<sup>9</sup> and World Health Assembly global action plan<sup>5</sup> both call for a doubling of research on dementia by 2025; it is important that such targeted increases are seen across all types of research and that current gaps are actively addressed. There is also a need to increase research capacity and capability, so that the community is able to compete successfully for available research resources. For the United Kingdom specifically, plans to mitigate possible negative impacts of Brexit (the United Kingdom leaving the

European Union [EU]) and possible loss of access to EU research funds will be needed.

2. Streamlining set-up processes of research

The time lag between a funder awarding a research grant and participants being recruited to a study is often many months or even years and may be subject to barriers and delays. Specific, and increasing, problems are reported by researchers around ethics and research governance permissions. Everyone involved in this process should address the unwarranted causes of delay and promote efficiency and equity.

3. Advancing public and patient involvement

There have been major increases in the ways in which members of the public and patients (or care users and those affected by dementia)

**TABLE 3** Goal 3 and recommendations**Improve Quality of Life for People Affected by Dementia by Promoting Functional Capabilities and Independence While Preventing and Treating Negative Consequences of Dementia**

1. Develop and evaluate a wide range of care, support, and self-management approaches that promote everyday functioning, well-being, and independence of people at all stages of dementia.
2. Develop and evaluate approaches that prevent or treat illness-related symptoms and consequences of dementia. Areas for priority development include the following:
  - Depression, anxiety, apathy, psychosis, agitation, and sleep disturbance
  - Pain, infections, falls, and incontinence
  - Nutrition and hydration
  - Physical functioning and mobility following illness or injury
  - Distress, depression, and anxiety among carers of people with dementia.
3. Demonstrate frameworks to evaluate how technology can enhance quality of life for people affected by dementia without replacing access to personally delivered care. Focus on cocreation of technologies and test their acceptability and practicality.
4. Research and evaluate community approaches that support social interaction and inclusion of people affected by dementia.
5. Use existing datasets and new longitudinal studies of people living with dementia to understand what factors are important to quality of life and how to enhance it.
6. Understand and meet the needs of people with severe dementia to optimise quality of life.
7. Design and evaluate types and layout of housing, care settings, transport facilities, community and public spaces, and natural environments that can support people affected by dementia to maintain independence, social engagement, and well-being.
8. Develop sustainable and scalable ways to support and enable family and other carers of people with dementia, recognising intergenerational aspects of caring and the diversity of carer roles within families and social networks.
9. Develop and promote the use of research designs that allow for intervention development and testing that does the following:
  - Considers the level of evidence needed in proportion to the goals of the research, practicality, potential harm, and intervention costs
  - Includes methodologically robust approaches to public and patient involvement and coproduction
  - Allows personalisation of interventions
  - Provides understanding of how interventions work
  - Shows how interventions can be implemented in real-world settings.
10. Work with people affected by dementia and professionals to identify and develop outcome measures that recognise benefits that are important to people living with dementia:
  - Develop techniques that consider outcomes across dyads or family units and the unique relationships between each.

**TABLE 4** Goal 4 and recommendations**Enable the Dementia Workforce to Deliver Improved Practice by Increasing Knowledge and Informing Changes in Practice and Culture**

1. Understand the essential skills and values needed to deliver effective dementia care and ensure that the key workforces are equipped with these.
2. Identify factors that influence the transfer of short-term and long-term learning to sustain improvements in practice.
  - Apply theories of how people learn in the development and delivery of training and resources
  - Identify the cultural and environmental attributes of organisations that support the application and sustainability of learning into practice.
3. Identify factors that predict, and strategies to enable, improved job performance, job satisfaction, and retention in the workforce engaged in dementia care, leading to better outcomes for people affected by dementia.
  - Evaluate strategies that aim to promote, attract, and retain more people with the values or capacity to work well with people with dementia and carers.

**TABLE 5** Goal 5 and recommendations**Optimise Quality and Inclusivity of Health and Social Care systems That Support People Affected by Dementia**

1. Evaluate health and social care dementia services from prediagnosis to end of life:
  - Monitor the flow of people through care systems, considering unmet needs for people with dementia, families, services, and care systems to identify evidence gaps and future research priorities.
  - Understand how services adapt to changes in external environment and individuals' needs.
2. Identify how best to support people affected by dementia to access services and secure the necessary funding
  - Understand the funding streams and structures that are available in the commissioning and purchasing of dementia services and support
  - Improve the way in which quality of dementia care is measured and communicated to provide assurance to carers and families
  - Understand the level to which care is self-funded, and the quality and value of care that people who pay for the services themselves receive.
3. Understand variations in the types, quality, and costs of care that people affected by dementia receive. Research should include seldom heard populations, such as minority groups and those who do not have family support.
4. Identify effective models of end-of-life care for people with dementia, taking into account that people may die with dementia before reaching the severe stages.
5. Develop and test innovative models of support that coordinate health and social care together with community-based support, care homes, housing, and voluntary sector services.

are involved in research. This is an important step forward, but there remains a need to make this involvement easier for people with dementia and their carers, and for the researchers. Such involvement needs to be proportionate and appropriate to the type of research, a subject requiring evidence in its own right.

#### 4. Advancing research methods

Methodological innovation, development, and refinement should be integral to most research projects, but there are opportunities in dementia research to develop consensus and sharing of emerging as well as established methods.

#### 5. Enabling research to be more inclusive

While not all research studies need to be representative of the population under study in every aspect, the national output of research should inform care and treatment for all. All research funding and then outputs should assess and actively report whether this issue of provenance and representation is important, and if not, why not.

#### 6. Initiatives to support study recruitment

We need to increase the number of routes through which people at all stages of dementia, including presymptomatic stages, have opportunities to take part in research studies. Innovation and plurality in routes to recruitment may help increase research in traditionally under-researched settings or areas and support inclusivity of research.

#### 7. Increasing data storage and reanalysis

Improving curation, storage, sharing, linkage, and reanalysis of data in dementia care, including qualitative data, is seen as an opportunity but requires specific focus to become established practice. Barriers include inefficient, repetitive ethics and governance processes and disproportionate rules regarding data protection.

#### 8. Increase involvement of professional stakeholders in research

While the involvement of people affected by dementia is now expected in research, the regular involvement of practitioners, service providers, and commissioners or funders from across all relevant sectors is less well established. Greater involvement of these stakeholders will help to ensure that research addresses practice or service-relevant problems and develops solutions that are more likely to be acceptable and implemented in the real world.

#### 9. Support knowledge exchange and research practices that facilitate uptake and implementation of findings

Linked to the need for involving professional stakeholders, researchers could be supported in enabling effective knowledge exchange with relevant audiences. More can be done to ensure that approaches used in research and the presentation of outputs make

research more digestible and applicable for those who commission, develop, deliver, and use services, and other stakeholders who implement research evidence. Researchers and funders should consider and measure mechanisms of action to ensure that all research findings (including negative ones) advance available evidence and our collective knowledge.

#### 10. Creating effective researcher networks

Enhancing opportunities for researchers to coordinate and collaborate regionally, nationally, and internationally will support larger and more ambitious research, support the sharing of knowledge and best practice, and will reduce the unnecessary duplication of some research. Dementia research will be strengthened by working across disease areas where there is overlap and by bridging research disciplines that have not traditionally been funded for dementia research.

## 4 | DISCUSSION

We have developed recommendations to advance research on prevention, diagnosis, intervention, and care in dementia, focusing on real-world outcomes. These are conceived so as to support policy frameworks for the care and support that people with dementia should receive, and the ambitions of the National 2020 Plan on Dementia,<sup>9</sup> the Scottish National Dementia Strategy 2017–2020,<sup>10</sup> Northern Ireland regional strategy,<sup>11</sup> and the forthcoming Welsh Strategy.<sup>12</sup> A common feature of these 4 strategies is to include commitments to research, but this is predominantly framed as focusing on funding discovery and biomedical research, instead of the contribution of research and evidence to underpin other strategy commitments. The research recommendations presented here, if followed, provide an opportunity for closer alignment of research to support the outcomes described in national policy and strategy.

There have been several dementia research road maps developed to date, but their implementation remains a challenge.<sup>5–8</sup> Effective implementation of this road map will require funding, a high level of coordination between different stakeholders, and maintained high-level national priority to be given to dementia. The mix of stakeholder groups included in the development of the road map includes researchers, clinicians, policymakers, and research funders from both government and third sector, which may be a facilitator to seeing the implementation of recommendations made in the road map. The National 2020 Plan on Dementia is stated to be due “for review and refresh during 2018 ... to set out firm deliverables for the final two years of the 2020 Challenge,”<sup>9</sup> which provides an opportunity for some recommendations in this road map to be considered for wider adoption.

While we present these recommendations in a UK context, there is synergy with other European and global initiatives. The EU-funded Joint Programming in Neurodegenerative Diseases aims to increase coordination and alignment of research activities between participating countries and has facilitated work on longitudinal cohorts, assisted living, and palliative care in dementia.<sup>13</sup> The Alzheimer's Association National Plan Care and Support Milestone Workgroup developed a

broad set of recommendations that included research milestones, but also awareness raising, workforce development, training, and policy, and practice developments.<sup>14</sup> The US milestones related to research include convening an annual working group to update on the state of dementia care research, comparative effectiveness research, and pragmatic and adaptive research methods that might be particularly suitable for international collaborations and activity.<sup>14</sup>

Total investment in dementia care research is not routinely measured in the United Kingdom but is far less than 0.1% of the estimated £26 billion annual cost of dementia to the UK economy.<sup>15</sup> Greater investment in clinical and care research will support more effective use of money spent supporting people with dementia, by ensuring that it is spent well. Greater investment in the research outlined here may save resources in the short, medium, and longer terms, as well as reducing excess harm, disability, and distress associated with ineffective care. There will be sections of the population at high risk of future dementia who may be benefitted by the drug discovery programmes in place, but dementia is a complex disorder, and most of those who develop it are often in their ninth decade and older with multiple contributing factors.

## 5 | CONCLUSION

The societal approach to research for dementia therefore needs to address the fact that there will be people with dementia in all societies for the foreseeable future. Thus, an equally strong focus to match drug discovery is urgently needed for the priorities outlined here supporting prevention, diagnosis, intervention, and care, vital for society as a whole and for people with dementia and their carers in particular.

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