Dementia research roadmap for prevention, diagnosis, intervention and care by 2025

An opportunity to align national dementia strategies and research

Alzheimer's Society, January 2018

Alzheimer's Society
United Against Dementia

Foreword

Recent years have seen a significant increase in the amount of money invested into dementia research. While this is hugely positive, people with dementia tell us that discovering new drugs should be only one part of the research effort and Alzheimer's Society agrees.

Much of the research to date has been aimed at finding a cure for dementia in the long term rather than improving the lives of people living with dementia today.

Alzheimer's Society is taking action to change this. We want to see research into dementia care, prevention and diagnosis on an equal footing with that focused on a cure for dementia. This research can show us how to deliver effectively on the policy commitments made in the Prime Minister's challenge on dementia 2020 and the dementia strategies of the devolved nations of Scotland, Wales and Northern Ireland.

To address the imbalance of funding, we have been working with a taskforce of leading dementia clinicians and researchers, patient representatives and other research funders to set out our collective ambitions for research into these vital areas. We started by asking the following question:

'What research, in addition to searching for new treatments, is required to improve the lives of people affected by dementia today, and reduce the risk of dementia for future populations?'

Alongside the global goal of finding a disease-modifying therapy for dementia by 2025, this roadmap puts forward five goals that aim to have far-reaching impacts for people already living with dementia as well as future generations. These goals are not just for the research community. They concern anybody with a stake in dementia research including people with dementia, health and social care professionals and those involved with public health programmes. We ask you all to consider how you can contribute to implementing these ambitions.

This work is an important first step towards achieving parity of investment between research for a cure and other areas, but any roadmap document won't transform dementia research on its own. Now the hard work starts. We're calling for researchers, funders and research delivery partners to work with us to turn these recommendations into a reality.

James Pickett
Head of Research, Alzheimer's Society

Contents

Introduction

In 2018, it is estimated that 50 million people are living with dementia globally, with similar numbers of carers and family members also facing the impact of dementia on their daily lives. In the last few years there has been increased global action on dementia as governments realise that future projections of care needs and costs present huge challenges, and that dementia is now the biggest killer in the UK.

In 2013 G7 countries announced the ambition of identifying a cure or disease-modifying therapy for dementia by 2025. We also saw the beginnings of a significant increase in the amount of global funding for research to reach that goal. For example, the global Dementia Discovery Fund with an initial budget of £83m ($100m) was established and in the UK and the UK Dementia Research Institute has been created with an initial £250m budget and a predominant focus on understanding biological mechanisms of disease.

As well as a global response to the scale of dementia, there has also been a national response at a country level. There is now a Prime Minister's challenge on dementia 2020 for England along with an implementation plan, and separate dementia strategies for Scotland, Northern Ireland and Wales (the Welsh dementia strategy is currently in draft form).

These strategies include common themes on ensuring equitable access for all people with dementia to best practice diagnosis and support, transforming services and models of care, and creating dementia-friendly communities and environments. By contrast however, only modest funding increases for research have been made available to generate the key evidence that will underpin these commitments.

Alzheimer's Society has recognised the power of setting an ambitious target to find a cure for dementia as a way to focus research efforts. We have established a taskforce of leading clinicians and researchers in dementia, research funders and patient representatives to develop additional ambitions for research into dementia diagnosis, prevention, treatment and care interventions. We asked the question:

'What research, in addition to searching for new treatments, is required to improve the lives of people affected by dementia today, and reduce the risk of dementia for future populations?'

The answer to this question provides an opportunity for closer alignment of research to support the outcomes described in national dementia strategies (see Further reading, page 27). We also widened our focus to include those at risk of dementia and risk reduction approaches, since this is a core theme of the Prime Minister's challenge on dementia 2020 for England.

Outcomes and goals

In this report we present the outcomes of work spanning nine months. There are five new goals that address prevention, diagnosis, quality of life of people with dementia and carers, dementia workforce and care systems. We recognise the interdisciplinary nature of research needed to make most progress against these goals and do not exclude biomedical research. Throughout, we consider the impact on people affected by dementia to mean those living with dementia, but also carers, families and wider communities.

For each goal, a number of specific recommendations are proposed that form the basis of a broad and inclusive research agenda. We have also developed an action plan that will help to support the implementation of the recommendations. These suggest ways to develop the research environment and infrastructure to enable researchers to address these important questions.

The goals, recommendations and actions are intended to be used by researchers who can respond through research proposals, and for funders and research-policy stakeholders who can influence the availability and direction of research funding and the research environment.

Our five goals are intended to sit equally alongside the ambition to develop and test new disease-modifying therapies. This document is intended to provide guidance and inspiration to researchers, funders and all stakeholders in dementia research about how increased co-ordinated action can improve lives in a meaningful and tangible way by 2025.

Goals and recommendations

1

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 through:
- collection of robust surveillance data on new incidence and prevalence of dementia in the UK population
- seeking better understanding of the causal reasons for recent changes in rates of dementia
- conducting long-term studies that clarify the direction of causality
- study of 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 by:
- increasing brain donation from cohorts to correlate brain changes observed through investigating neuropathology with epidemiological findings
- routine linking of cohort data to healthcare 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 through:
- establishing the intensity of interventions needed to modify risk of developing dementia, for individuals and groups with different baseline levels of risk
- researching the motivations for behaviour change in lifestyle factors relevant to risk of dementia at both individual and societal levels
- establishing and validating sensitive measures in healthy adults that predict delay in onset or prevention of dementia
- use of precision medicine (for example. genetics, 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.

2

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 be 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, in order 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 UK in order to:
- understand regional, demographic, socio-economic 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 post-diagnostic 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 non-invasive tests that support making a diagnosis in primary care, and tests in specialised memory services such as CSF lumbar puncture and molecular PET 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.

3

Improve the 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, wellbeing 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, for example:
- 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 co-creation 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 wellbeing.

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:
- 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 co-production
- 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. Consider:
- development of techniques that consider outcomes across dyads or family units and the unique relationships between each.

4

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 by:
- applying theories of how people learn in the development and delivery of training and resources
- identifying 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 dementia care workforce, leading to better outcomes for people affected by dementia. Include:
- evaluating strategies that aim to promote, attract and retain more people with the values or capacity to work well with people with dementia and carers.

5

Optimise the quality and inclusivity of health and social care systems that support people affected by dementia

1 Evaluate health and social care dementia services from pre-diagnosis to end of life, including:
- monitoring 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
- understanding how services adapt to changes in external environment and individuals' needs
- asking how clinical and care pathways can best accommodate the needs of people with dementia.

2 Identify how best to support people affected by dementia to access services and secure the necessary funding by:
- understanding the funding streams and structures that are available in the commissioning and purchasing of dementia services and support
- improving the way in which quality of dementia care is measured and communicated to provide assurance to carers and families
- understanding 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 co-ordinate health and social care together with community-based support, care homes, housing and voluntary sector services.

An action plan to deliver the research roadmap

The growth in awareness and prioritisation of dementia as a global issue gives us an unprecedented opportunity to enhance the efficiency and effectiveness of research.

This will necessitate addressing barriers that hold back the design, delivery and dissemination of research and its adoption into practice and policy. The action plan outlined in this section sets out proposals to see research delivered at greater scale, more inclusively and with greater impact for people affected by dementia.

Specific actions may include targeted initiatives or the development of new resources, as well as workshops or national 'start and finish' groups.

1. Increasing funding available for research

The Prime Minister's challenge on dementia 2020 for England and the World Health Organization's global dementia action plan both call for a doubling of investment into dementia research 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 UK specifically, plans to mitigate possible negative impacts of Brexit and possible loss of access to EU research funds will be needed.

2. Streamlining set-up processes for 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. Researchers report specific and increasing problems 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 patient and public involvement

There has been a major increase in the ways in which patients and members of the public are involved in research. This is largely welcomed, 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. Researchers and funders should consider and measure processes to ensure that all research findings (including negative ones) contribute to available evidence and advance our collective knowledge.

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 outputs should assess and actively report whether this issue of provenance and representation is important, and if not why not. Where it is clear that particular groups are being excluded, it is important that the issue is addressed.

6. Initiatives to support study recruitment

We need to increase the number of routes through which people at all stages of dementia, including pre-symptomatic stages, have opportunities to take part in research studies. Innovation and plurality in routes to recruitment may help to 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.

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

Researchers could be supported to enable 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 policy-makers as well as those who commission, develop, deliver and use services and other stakeholders who implement research evidence.

9. Increase involvement of professional stakeholders in research

Although 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.

10. Creating effective researcher networks

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

Specific proposals for the action plan

We held a workshop in August 2017 with 25 attendees and ran an online consultation with 60 individuals to develop the action plan. Specific suggestions are listed below, grouped under the key areas of focus that may contribute to the delivery of the proposed actions. These actions may require additional scoping, for example to understand how they fit in with existing initiatives and activities.

Increasing funding available for research

- Report the national annual spend on research, and include a breakdown by type and aim of research.

- Produce regular national reports on the quantity, quality, breadth and impact of dementia research.

- Agree and set a national target for research funding as a percentage of the economic cost of dementia.

Streamlining set-up processes for research

- Audit research grant holders to identify time lags in the launch of research. Work with other AMRC charities to gather the same information so we can compare across sectors to identify dementia-specific barriers.

- Survey recent researcher experiences on process and outcomes of obtaining ethics and governance approvals for studies involving people with dementia, as well as the perspectives from R&D and ethics committees. Working with the Health Research Authority, use evidence to improve the system for all.

- Support people affected by dementia to co-design templates for patient information sheets, consent forms and other common recruitment documents that can be made widely available to researchers to use and adapt, and evidence can be made available that these will be acceptable to ethics committees. Work on this could be part of a 'task and finish' group.

Advance patient and public involvement

- Develop further guidelines support to explore if it is possible to financially reimburse or pay people for participating in research that does not involve contracts or impact on tax and benefits – this could also create a more representative group of research participants. There is a view that the current system reinforces imbalance in inclusion, for example only those that can afford not to be paid for their time.

- Develop guidelines and processes for supporting involvement and participation of people affected by dementia in commercial clinical research.

- Develop a good practice guide and materials for ethics committees on lay co-researchers. Some researchers perceive that including co-researchers can create a barrier in seeking ethics and R&D approval for research.

- Develop a good practice guide on the involvement of people affected by dementia in research including those in later stages or with profound communication problems.

- Standardise reporting in journals and project reports on the impact (positive and negative) that involving people with dementia has in research; develop a system whereby funders request the reporting of this information in reports and journal articles.

Enabling research to be more inclusive

- Grant application forms/websites should include mandatory sections to address how inclusivity is ensured, and a statement on equality of opportunity similar to those used in recruitment for jobs. Available funding for this should be acknowledged.

- Funding boards and peer reviewers to scrutinise exclusion criteria and only permit well-argued exceptions.

- Create a national working group to consider the representation of participants recruited in research studies, and make recommendations to address under-researched groups. This requires scoping reviews to examine hard to reach dimensions, and consensus on frequently used terms such as 'older' people.

- Identify ways to ensure that non-family carers (such as friends and neighbours) have the same opportunities as family carers to participate in research.

- Provide specific funding (ideally mandated by funders as part of the main trial analysis) for secondary analysis of trial data to examine the effects of gender, class and other factors, and use improved understanding to target and personalise interactions

- Develop a standard, acceptable process for how people who have been assessed to be lacking capacity under the Mental Capacity Act 2005 can make the specific decision to participate in a study and be involved in research, and explore wider mechanisms for establishing enduring informed consent.

Actions on increasing efficiency in recruitment

- Set ambitious national targets for involving people affected by dementia in research.

- Funders to address the funding gap for intervention costs in non-NHS settings (such as day centres or care homes).

- Develop further support for the distribution and access of funding for excess treatment costs in NHS settings.

- Develop a framework for research in each type of setting, for example the NIHR ENRICH Network for research in care homes could be expanded to other settings and demographics.

Actions on advancing research methods

- Workshop/national task and finish group to identify appropriate level of evidence needed for different types of intervention to be implemented (considering potential costs of intervention or potential harms). Make recommendations for effective data collection and outcome measurement across the dementia pathway, including at diagnosis, post-diagnosis and through to end of life.

- Establish a focused initiative on methods for including people with severe dementia in research, and develop of meaningful outcome measures for people with severe dementia.

- Encourage a funding call to scope current research on the testing of the validity of outcome measures and methods currently being used in dementia research.

- Create a platform (virtual or in combination with a publisher) to share research case studies examples with a spotlight on the methodology of projects, including barriers, challenges and limitations, as opposed to the research outputs.

- Develop recommendations to ensure methodologically robust involvement of people affected by dementia in research studies.

Increasing data storage and reanalysis

- Funders should mandate that data sharing is considered in grant applications, and provide funding for this activity.

- Develop improved consent processes such as including consent for anonymous access to participant data in future studies. Guidance may be required early on in studies since such complications are a perceived barrier in gaining ethic permissions.

- Develop a central data-signposting platform, to include guidance on ethics of data sharing and consent.

- Make opportunities for specific funding available for secondary analysis of existing data sets.

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

- Funders to require communication, knowledge exchange and impact activities are adequately budgeted for within research grants.

- Create a directory of companies and professionals willing to provide pro bono support to the communication of research findings.

- Develop guidance on good practice for disseminating research to people affected by dementia.

- Develop mechanisms for embedding research findings into the curricula of higher education programmes for health and social care professionals such as nursing, occupational therapy, physiotherapy and social work.

- Establish the need for a UK-wide dementia care research conference.

- Funders and researchers to collaborate on developing guidance to enable service providers to assess the quality of available evidence for an intervention before proceeding with implementation.

- Develop reporting guidelines to enable higher quality and more standardised publication of implementation projects.

Methodology

Increase involvement of professional stakeholders in research

■ Establish research interest groups within practitioner networks to gather their ideas and needs for new research (examples include care homes, homecare, assisted living and other housing providers, social workers).

■ Dementia policy stakeholders to define data needs and develop a national plan for surveillance of dementia in the population to enable policy and future resource planning, and commission as necessary.

■ CQC and HealthWatch to include information about participation in research in their published assessments.

Creating effective researcher networks

■ Develop a UK specific network that focuses on psychosocial interventions, providing links to INTERDEM.

■ Develop and maintain a web portal that fosters communication of research findings, a sense of helping to understand the existing landscape, and cohesiveness of the research community.

■ Collaborate with funders and researchers working across common symptoms of complex diseases, such as continence, reducing falls and mental health.

■ Funders to offer research development grants to enable researchers to work together across disciplines to submit complex research proposals.

■ Single-disease funders to increase mechanisms for funding co- and multi-morbidity studies across funders.

■ Engage and encourage NIHR Research Design Service in dementia-specific initiatives.

Alzheimer's Society convened a taskforce composed of leading academic researchers, clinicians, patient representatives and relevant stakeholders (see page 26) who worked together in the first nine months of 2017 to deliver this work. The taskforce first met in January 2017 to conceptualise the research goals, and then participated in five goal-specific teleconferences to develop recommendations.

The taskforce met again in April 2017 to review and revise the first version of the roadmap. Alzheimer's Society consulted on the first draft of the roadmap with members of the Alzheimer's Society Research Network composed of people living with dementia, carers and former carers and ran a consultation workshop at Alzheimer's Society annual conference in May 2017.

An online survey inviting feedback on goals and recommendations was widely distributed in June 2017 and completed by 60 participants. These were mostly researchers or academics with health and social care experience and a minority number of people affected by dementia.

The taskforce met in August 2017 to redraft the roadmap based on the collected feedback. An action plan to support the implementation of the roadmap was developed alongside goals and recommendations, specifically during a half-day workshop in August 2017 with members of the taskforce as well as additional stakeholders and representatives of people affected by dementia.

Membership of the taskforce

Members
Cathy Bird, lay member, Research Network volunteer
Clive Ballard, University of Exeter
Sube Banerjee, Brighton & Sussex Medical, School
Carol Brayne, University of Cambridge
Linda Clare, University of Exeter
Adelina Comas, LSE
Lynne Corner, University of Newcastle
Stephanie Daley, BSMS
Martin Knapp, LSE
Louise La Fortune, University of Cambridge
Gill Livingston, UCL
Jill Manthorpe, King's College London
Natalie Marchant, UCL
Jo Moriarty, King's College London
Louise Robinson, University of Newcastle
Gill Windle, Bangor University
Bob Woods, Bangor University

Funders
James Pickett, Clare Walton, Katherine Gray, Alzheimer's Society
Rosa Sancho, Clare van Lynden, Alzheimer's Research UK
Joy Todd, Jo Goddard, ESRC
John Wilkinson, NIHR

Facilitator
Katherine Cowan, independent facilitator

Additional attendees of the action planning workshop
Robyn Polisano, Department of Health
Carmel Hughes, Queen's University Belfast
Charlotte Clarke, University of Edinburgh
Jan Oyebode, University of Bradford
Sue Dewhirst, Public Health England
Steve Iliffe, UCL
Martin Rossor, UCL
Libby Archer, World Dementia Council
Sue Boex, Frank Arrojo, Shirley Nurock, Jean Collins, Dick Abbott, Peter Riley, Jane Ward,
lay members of Alzheimer's Society's Research Network

Further reading

National dementia strategies and plans:

Prime Minister's challenge on dementia 2020
www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020

Scotland's National Dementia Strategy 2017–2020
www.gov.scot/Publications/2017/06/7735

Improving dementia services in Northern Ireland: A regional strategy
www.health-ni.gov.uk/sites/default/files/publications/dhssps/improving-dementia-services-2011.pdf

Welsh Government, Together for a Dementia Friendly Wales 2017–22
https://consultations.gov.wales/consultations/draft-national-dementia-strategy

WHO Global action plan on the public health response to dementia 2017–2025
http://apps.who.int/gb/ebwha/pdf_files/EB140/B140_28-en.pdf?ua=1

Dementia devastates lives. By 2021, 1 million people will be living with the condition. But dementia won't win. Until the day we find a cure, Alzheimer's Society will be here for anyone affected by dementia – wherever they are, whatever they're going through. Everything we do is informed and inspired by them.

We are the UK's leading dementia charity. Every day, we work tirelessly to find new treatments and, ultimately, a cure for dementia. We provide expert information, training, and support services to all those who need our help. And we are creating a more dementia friendly society so people with the condition can live without fear and prejudice.

Let's take on dementia together. Volunteer. Donate. Campaign for change. Whatever you do, unite with us against dementia. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)