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Australian Government Department of Health and Ageing

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National Dementia Action Plan

Response to the Consultation Paper

Introduction

Research Australia welcomes the opportunity to make this submission in response to the National Dementia Plan Consultation paper. As the national peak body for the Australian health and medical research and innovation sector, our submission is focused on *Objective 7: Improving dementia data and maximising the impact of dementia research and innovation*.

Research Australia welcomes the inclusion of research and innovation in the National Dementia Plan and the emphasis on ensuring research and innovation lead to tangible outcomes for people living with dementia, their carers and families. We are concerned however, that the consultation paper has failed to recognise the actions needed to make this ambition a reality.

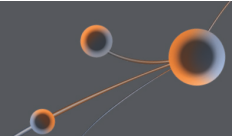
Our submission seeks to address this issue.

Objective 7: Improving dementia data and maximising the impact of dementia research and innovation.

Data

Research Australia agrees that the limited Australian data on dementia diagnosis and management is a challenge that needs to be addressed and broadly agrees with the actions outlined at 7.3 and 7.4 to improve the collection of data and its use.

Data is critical to research, and better data can improve the scope and effectiveness of research that can be undertaken. While the specific action to improve clinical coding



references research uses of data, the other actions are silent on access to data for research. There is a proposed action to develop a national dementia data framework, but no detail on the framework or how it will be utilised.

Research Australia submits the proposed national dementia data framework should be developed from the outset with an explicit objective of improving access to data for research purposes.

Research and innovation

The first action identified under the Focus Area of Advancing Dementia Research and Innovation is 'Developing an Australian dementia research strategy that enables people with lived experience, including those from priority population groups, to work with researchers, clinicians, academics, service providers and governments to inform research priorities.' (Page 65)

The NHMRC National Institute for Dementia Research was funded by the Government in 2014 as part of the five year \$200 million Boosting Dementia Research Initiative. Prior to its closure in 2020, the NNIDR developed:

- a Strategic Roadmap for Dementia Research and Translation
- a Culturally and Linguistically Diverse (CALD) Dementia Research Action Plan
- an Aboriginal and Torres Strait Islander Roadmap for Dementia Research Translation

The NNIDR also produced a number of other reports and guidelines, including 'Becoming Involved in Research: A Guide for People Living with Dementia, their Care Partners and Family Members'. (One of the challenges identified in the Consultation paper is 'Limited engagement with people with lived experience'.)

Research Australia submits that these documents should form the basis for the Dementia Research Strategy proposed by the Consultation paper and could be readily adapted to the new strategy, thereby utilising already invested public funds and expertise as part of this exercise. All the documents continue to be available on the NNIDR website.

Maximising the impact of research and innovation

Research Australia welcomes the recognition in the consultation paper that when it comes to research '(t)here is often a lack of understanding on where the responsibility for translation into practice sits, and a disconnect between research and how this is then put into practice.' (Page 64) The disconnect referred to here is real, and is perpetuated by disparate funding schemes for research, innovation and training.

In the commercial environment, there is a focus on research and development; not only creating new knowledge but applying it to the development of new products and applications. Government funding for research typically stops at the 'research', with the 'development' too often neglected by both public funding bodies and private investors. This is frequently because the research has not been advanced to a sufficient stage to attract private investment, or because the application of the research is not commercially exploitable.

The Consultation Paper proposes two actions to address the disconnect between research and how it is put into practice. The first is 'Developing a centralised dementia research clearing house'. The second is 'Ensuring research considers implementation strategies and principles of knowledge translation'. While agreeing that these are important, Research Australia does not believe they will be sufficient.

Consider the example of a clinical trial to develop a new model of care for people living with dementia in residential aged care. The clinical trial is undertaken according to a strict trial protocol in several aged care settings chosen as trial sites and is conducted using additional staff and resources funded as part of the trial. At the conclusion of the trial, the staff and resources are withdrawn.

Assuming the trial has been successful, the new model of care is unlikely to be adopted even if 'implementation strategies and principles of knowledge translation have been considered' by the researchers, or the research is published in a clearing house.

Adoption of the new model of care into normal practice will not occur unless significant work has been undertaken to: develop an implementation plan; develop training materials and guides; train staff; and integrate the new model into existing work practices and standard operating procedures to ensure practice and importantly, accountability.

These activities are not currently funded by research grants provided by the NHMRC's Medical Research Endowment Account (MREA) or the Medical Research Future Fund. (See, for example, the list of eligible grant activities in the MRFF 2022 Dementia, Ageing and Aged Care Grant Opportunity Guidelines.) Equally, implementing these new models of care is not seen as business as usual by our already stretched aged care and healthcare workforces. It is even less likely that the new model of care will be adopted in settings that didn't participate in the clinical trial.

Neither the Action Plan nor the proposed Strategy currently make any provision for funding of the implementation activities needed to embed research into practice. Without this focus

on implementation, the Action Plan will not meet Objective 7, maximising the impact of dementia research and innovation.

Research Australia submits the Action Plan must explicitly recognise that the implementation and scaling of research initiatives (the ‘development’ in research and development) is an equally critical endeavour to undertaking research. The Action Plan must focus not only attention but funding on the activities that are required to enable research outputs and innovation to be translated into outcomes that can lead to impact, and appropriately resource these activities.

Research Australia submits that the proposed Australian Dementia Research Strategy should be an ‘Australian Dementia Research, Innovation and Implementation Strategy’ to better meet the Action Plan’s objective of maximising the impact of research and innovation.

Research Australia submits that accountability for implementation of research outcomes and the funding of this activity needs to be clearly assigned by the Action Plan and the Strategy.

Funding

The Strategy currently proposed by the Action Plan does not propose providing new funding for research, innovation or translation activities. Instead, ‘Increased research is undertaken through current funding arrangements’ is identified as an immediate performance measure.

The Strategy does not propose any actions that can be relied on to increase research funding for dementia through current funding arrangements; at the same time Research Australia is aware that several other Australian Government strategies, in areas as diverse as the National Medicines Policy, Primary care and obesity prevention, also propose to increase the share of the existing research funding for their target area. None of these strategies proposes any mechanism by which more funding will be directed to these strategies’ target area.

The demand on existing funding sources for research is intense, and they are already providing funding for dementia research. The MRFF is investing \$185 million over 10 years through its *Dementia, Ageing and Aged Care Mission*. The Roadmap for the Mission, finalised in September 2021, has identified the following research priorities in dementia:

- interventions that prevent or delay the onset of dementia symptoms
- care approaches to manage the impact of dementia on wellbeing and quality of life
- care and diagnostic pathways to enable timely diagnosis of dementia.

The NHMRC provides funding for health and medical research through the MREA. While the bulk of its funding is investigator driven and provided through its open competitive

programs, it does provide some targeted funding of around \$10 million per year. NHMRC expenditure on dementia research grants through the MREA's targeted and open competitive programs in 2021-22 was \$53.8 million.¹

How would the Action Plan fund new research without additional funding? What actions are proposed to be taken to make dementia research proposals more competitive relative to other funding applications than they currently are?

Research Australia submits the Action Plan and/or the proposed research strategy must provide concrete actions to increase funding for dementia research and innovation, and to improve implementation of new interventions. The identified actions, of creating a centralised clearing house, and increasing researchers' consideration of implementation strategies and principles of knowledge translation, will not be sufficient without funding to support implementation activities.

Conclusion

Research Australia shares the Government's view that Australian health and medical research and innovation can lead to a real and lasting improvement in the lives of those living with dementia, their families and carers.

Many of the pieces are in place, but impact is limited by a lack of coordination and resources to support research and innovation and its implementation. The Action Plan provides an opportunity to address these shortcomings, and we trust this brief submission has highlighted ways in which the Action Plan can be developed, including building on already invested public resources, to ensure we obtain maximum benefit from our research and innovation.

We are pleased to be of further assistance; please contact Greg Mullins, Head of Policy at greg.mullins@researchaustralia.org if you have any questions or require further information

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¹ Australian Government, NHMRC Annual Report 2021-22

ABOUT RESEARCH AUSTRALIA

Our vision: Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

Our mission: To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

Our role:

Engage

Australia in a conversation about the health benefits and economic value of its investment in health and medical research.

Connect

researchers, funders and consumers to increase investment in health and medical research from all sources.

Influence

government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes

Established with the assistance of the Federal Government in 2002, Research Australia is the national alliance representing the entire health and medical research (HMR) pipeline, from the laboratory to the patient and the marketplace. Research Australia works to position Australian HMR as a significant driver of a healthy population and a healthy economy.

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