

Australian Medical Research and Innovation Two Year Priorities

Title: Enhancing the capacity and impact of dementia research in Australia

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1. What is the gap in Australia's health system to be addressed by this priority?

The prevalence of dementia in Australia is set to increase from more than 350,000 people today to almost 900,000 by mid-century, bringing enormous social, health and aged care system, and economic impacts; yet dementia research funding and capacity lag behind other national health priorities.

2. How does your area of priority address either an existing or a new health or health system challenge?

Research into prevention, early intervention, treatment, and system responses will help equip Australia to meet the massive challenges the sharp increase in dementia prevalence will present to our primary health care, hospital, residential aged care, disability, and community care systems.

3. Comment on which aims and objectives your priority is likely to meet.

- An excellent and responsive health and medical research system that improves lives: Clinical and translational research will improve the lives of people with dementia and their carers.
- Prevention and cures of tomorrow: Evidence will be generated and used to reduce risk of dementia, and the vital search for effective curative treatments for dementia will continue.
- Economic benefits: Risk reduction and more effective treatments for dementia will reduce pressures and costs to the health and aged care system, and increase workforce participation.
- Sustainable, high quality, cost-effective health care: Evidence-based risk reduction and better care for dementia will lead to more effective and cost effective use of health resources.
- Leveraging and enhancing collaboration and integration: This proposal is built on collaboration and integration between the peak dementia body (which includes a philanthropy-based research foundation), an existing NHMRC research institute, researchers, consumers, and external stakeholders.
- A translation pathway that maximises opportunities for success: Engagement of providers in the health care, aged care, and disability systems will facilitate effective translation.
- Healthcare policy and delivery have a strong evidence base: Evidence generated through this initiative will support better healthcare policy and delivery with respect to dementia.
- Contemporary infrastructure that meets research needs: The utilisation of an existing NHMRC research institute will ensure the appropriate infrastructure to meet research needs.

4. Mandatory considerations – which of the mandatory considerations set out in the *Medical Research Future Fund Act (2015)* does your priority proposal address?

- Burden of disease on the Australian Community
- How to deliver practical benefits from medical research and medical innovation to as many Australians as possible
- How to ensure that financial assistance provides the greatest value for all Australians
- How to ensure that disbursements complement and enhance other assistance provided to the sector

5. Outline of priority proposal:

The current problem

Dementia is a national health priority area, the second leading cause of death overall¹, and the third leading cause of disability². Yet despite its major impact, funding for dementia research has lagged

¹ Australian Bureau of Statistics (2015). *Causes of death, Australia, 2013*.

² Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

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behind other national health priority areas for decades. The Government's commitment to increase funding for dementia research by \$200 million over five years from 2014, and the establishment of the NHMRC National Institute for Dementia Research (NNIDR) is a welcome investment. However, this investment is a short-term boost to dementia research with only a five year commitment of funding. Even with a short-term increase of approximately \$40 million pa, NHMRC funding for dementia research will still be a small fraction of the funding provided to other health priorities such as cancer and cardiovascular research. The dementia sector is not growing quickly enough to be able to compete in the research funding environment. We need to establish a cohort of future dementia researchers by attracting the best and brightest new researchers into the field at early and mid-career levels. To achieve this, a sustained increased investment in dementia research is needed.

It is also important to support consumer involvement in dementia-research. Alzheimer's Australia, with support from the Dementia Collaborative Research Centres, has developed a strong Consumer Network which facilitates active consumer involvement in a range of research programs and initiatives including the NHMRC Partnership Centre on Cognitive Decline. There is currently uncertainty regarding future funding for consumer involvement in dementia research.

The proposed solution

Sustained investment in dementia research is needed, encompassing risk reduction, care at all stages of the disease, and the search for effective curative treatments. The investment must support the translation of research into practice, to ensure that people with dementia and their families benefit through improved care and services. There is also a need to ensure that people with dementia and their families continue to have a strong voice in how research is prioritised and implemented. There is good evidence that consumer engagement in research improves methodology and leads to outcomes that are more relevant for the consumer.

A commitment is needed to increased investment in dementia research over a 10-year period to achieve a level of \$80 million pa by 2025. This would be equivalent to 50% of the current NHMRC funding for cancer research. Continued funding and support for consumer involvement in all aspects of dementia-research in Australia must be part of this approach.

It is proposed that the Medical Research Future Fund supports dementia research in Australia through additional funding for the NHMRC National Institute for Dementia Research (NNIDR), which was established in 2015 and currently operates under the auspices of Alzheimer's Australia. This additional funding would commence with \$5.2 million pa over the next two years. The funds will be used to:

- Increase scholarships, development grants, and project grants to early and mid-career researchers, to foster the development of dementia research capacity in Australia.
- Provide a centralised reference point for consumer participation in dementia research, including consumer access to research information, opportunities for consumers to advise on research, and opportunities for consumers to participate in research trials.
- Support both clinical research and translational research, maintaining the NHMRC categories.
- Create a clearinghouse of dementia research to inform future trials, streamline efforts, and draw on previous research more effectively.
- Develop a standardised reference guide and approach to dementia research in Australia, including assistance with recruitment of research participants.
- Link with health services, aged care services, disability services, and other stakeholders, to facilitate their participation in translational research.
- Include a focus on evaluation in all research trials and translational research.
- Provide continuity in driving collaborative and coordinated dementia research.
- Deliver funding to targeted priority-driven research in a non-traditional manner.

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Implementation feasibility

This is a highly feasible and immediately implementable proposal, as the NNIDR is already operational, and has strong links with relevant stakeholders including consumers through Alzheimer's Australia. This existing experience and expertise will be leveraged by this initiative.

Potential risks and mitigation strategies

Risk 1: NNIDR lacks capacity to implement the proposal. To be mitigated by ensuring an appropriate proportion of funding is retained to build and maintain capacity within NNIDR. Business plan for the implementation of additional funding to be developed at the outset.

Risk 2: Lack of stakeholder/researcher/consumer engagement. To be mitigated by targeted stakeholder engagement plans relating to consumers, researchers, and other external stakeholders.

6. What measures of success do you propose and what will be the impact on health care consumers?

- KPI 1: An agreed proportion of funding is disbursed as research grants with a demonstrably rigorous assessment process in place for grant funding.
- KPI 2: Proportion of research grants which lead to published research.
- KPI3: Proportion of research grants which lead to changes to dementia policy or services.
- KPI 3: Consumers have enhanced opportunities to participate in dementia research, and take advantage of these opportunities, with high levels of consumer satisfaction with the initiative.
- KPI 4: Both clinical and translational research are supported.
- KPI 5: A clearinghouse is established by the end of Year 1, and is actively utilised by researchers, consumers, and other stakeholders from Year 2 onwards.
- KPI 6: A standardised reference guide and approach to dementia research in Australia is in place, and there is evidence that researchers have been assisted with recruitment of research participants.
- KPI 7: There is evidence of effective linkages and partnerships with stakeholders.
- KPI 8: There is a focus on evaluation in all research trials and translational research.

7. Please outline any linkages your proposal has with stakeholders, policy agendas and other health and medical research funding agencies.

- National Health and Medical Research Council: This proposal builds on and strengthens the capacity of the NHMRC's National Institute for Dementia Research, leveraging existing experience and expertise.
- Industry, philanthropy, the taxation system, and other grants: The NNIDR operates under the auspices of Alzheimer's Australia and thus has close linkages with the national peak body, its Dementia Research Foundation which is supported by donor funds, and other work undertaken by Alzheimer's Australia through philanthropic or government grant funding.
- State and Territory health and medical research initiatives: Translational research will be undertaken in collaboration with health, community, and disability services funded by S/T governments, and linkages will be built with S/T health and medical research initiatives.
- The health system – medical, workforce, hospitals: Translational research will be undertaken in close collaboration with the health system.
- Commonwealth Health Portfolio priorities: Dementia has been identified as a national health priority area and is often co-morbid with other chronic diseases which are national priorities.
- Health and medical researchers: Researchers are already closely linked in with both Alzheimer's Australia and the NNIDR, and this proposal will build on those linkages. Linkages will also continue to be fostered with other relevant research hubs such as the Dementia Collaborative Research Centres.
- Consumers: This proposal builds on and enhances existing Alzheimer's Australia engagement with consumers.