dementia australia™

The new voice of Alzheimer's Australia

Australian Medical Research Advisory Board

Consultation on Australian Medical Research and Innovation Priorities for 2018-2021

Submission from Dementia Australia

July 2018

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 425,000 Australians living with dementia and the estimated 1.2 million Australians involved in their care.

Dementia Australia works with individuals and families, all levels of government, and other key stakeholders to ensure that people with dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with consumers means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

Background

Dementia Australia welcomes the opportunity to contribute to the Australian Medical Research Advisory Board (AMRAB)'s national consultation to inform the development of the second set of Medical Research Future Fund (MRFF) Australian Medical Research and Innovation Priorities (Priorities) for 2018-2020.

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease. Dementia can happen to anybody, but it is more common after the age of 65.

Dementia is not a natural part of ageing. It is a terminal condition and there is currently no cure. Dementia is one of the largest health and social challenges facing Australia and the world. It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.[1]

Dementia affects people's functional abilities and memories and has a profound impact on the individual and those around them.[2] The disease is cloaked in stigma and misunderstanding,[3] isolates people with dementia and their carers from social networks,[4] and carries significant social and economic consequences.[5] People living with dementia constitute one of the most vulnerable groups in our society.

There are more than 425,000 Australians living with dementia in 2018 (including 25,000 people under the age of 65 years with younger onset dementia) and, without a significant medical breakthrough, there will be over one million people living with dementia in Australia by 2056.[6] It is estimated that there are approximately 1.2 million Australians involved in the care of people living with dementia.[7]

The cost of dementia to the Australian economy is significant and growing rapidly. In 2018, dementia is estimated to cost Australia more than $15 billion. By 2025, the total cost of dementia is predicted to increase to more than $18.7 billion in today's dollars, and by 2056, to more than $36.8 billion.[8]

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1 Australian Bureau of Statistics (2016) *Australia's leading causes of death* Available online at http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2016~Main%20Features~Australia's%20leading%20causes%20of%20death,%202016~3

2 Mitchell, S. et al. (2009) The clinical course of advanced dementia, *The New England Journal of Medicine*, 361: 1529-38

3 George, D. (2010) Overcoming the 'Social Death' of dementia through language, *The Lancet*, 376: 586-87

4 Blay, S. & Peluso, E. (2010) Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2): 163-7

5 Access Economics (2003) *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Alzheimer's Australia, Available online at: www.fightdementia.org.au/research-publications/access-economics-reports.aspx

6 The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2016) *Economic Cost of Dementia in Australia 2016-2056*

7 Alzheimer's Australia (2011) *Pfizer Health Report Issue #45 – Dementia*, Pfizer Australia

8 The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2016) *Economic Cost of Dementia in Australia 2016-2056*

Responses to consultation questions

1. Are there any outstanding Priorities from 2016-2018 that need to be extended or re-emphasised?

Dementia Australia commends the MRFF Strategy and Priorities and recommends that continued investments are made in international collaborative research, targeted translation topics and building evidence in primary care, with specific attention given to dementia research.

Dementia is a national health priority area, the leading cause of death for women, the second leading cause of death overall[9] and the third leading cause of disability[10]. Yet despite its significant and far reaching impact, funding for dementia research has lagged behind other national health priority areas for decades. The Government's commitment in 2014 to increase funding for dementia research by $200 million over five years with the establishment of the NHMRC National Institute for Dementia Research (NNIDR) has been a welcome investment. It has helped to transform the dementia research landscape in Australia, through funding over 100 new clinicians, scientists and health professionals all of whom are carrying out research programs, many with an international impact and in collaboration with new and existing groups.

The NNIDR's Boosting Dementia Research Initiative (BDRI) research portfolio investments demonstrate a consistency with MRFF Strategy and Priorities, funding high calibre dementia researchers to undertake large-scale collaborative projects, connected to and furthering the international research effort. The largest BDRI investment to date has been in the National Dementia Network, which is establishing as part of its national framework and programs a clinical quality registry. NNIDR is working with the Australian Bureau of Statistics and Australian Institute of Health and Welfare to strengthen dementia data methods and statistics, including looking at novel sources and means to establish reliable estimates on dementia incidence and prevalence. Significant investments have been made to build the dementia interventions evidence base for clinical practice and build workforce capacity.

However, this investment is a short-term boost to dementia research with only a five year commitment of funding. Even with this short-term increase of approximately $40 million per annum, funding for dementia research will still be a small fraction of the funding provided to other health priorities such as cancer and cardiovascular research. It is imperative that we are able to retain and grow this new cohort of dementia researchers by continuing to attract and retain the best and brightest new researchers into the field at early and mid-career levels.

While the full gamut of dementia research – from prevention to cure – is urgently required, the more immediate quality of life improvement for people impacted by dementia is likely to arise from behavioural and social research.

There is also an urgent need that Australia retains and builds on this new research capacity so as to allow us to participate in international clinical trials aimed at delaying the onset of dementia, and offering new forms of treatment.

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

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

2. What are the unaddressed gaps in knowledge, capacity and effort across the healthcare continuum and research pipeline?

Dementia Australia strongly advocates for greater investment in the health services implementation science that could hasten translation of new evidence into the health system, alongside continuing investment in building evidence in primary care. Dementia Australia supports continuing investment in the Biomedical Translation Fund and seeks a greater emphasis in any current and future biomedical research and commercialisation support schemes on investments toward the translation of newly identified dementia targets and mechanisms for the possible treatment of dementias.

Research needs to be able to facilitate answers to the full spectrum of social and clinical challenges, from dementia causes, to risk reduction and prevention, the impact of dementia on carer and family, quality of life issues, social isolation, disease management, care, treatment and ultimately, a cure. With no currently available treatment that will significantly delay or treat dementia, and given the increasing burden to the health system that dementia represents, priority needs to be given to continuing and new dementia research investments from the benchtop to the bedside.

Further, there is still a significant delay between research being funded and the translation of research findings to practice. It is estimated that it can take up to 25 years for research evidence to reach clinical practice.[11] This delay manifests itself as poor outcomes for people living with dementia. For example, research has shown that behavioural and psychological symptoms of dementia (BPSD) are often transitory, with symptoms at times only lasting a few weeks or months and rarely more than two years. Some research has shown that psychosocial interventions are most effective and pharmacological treatment should therefore not be the first line response to address these symptoms. But it is estimated that up to 70,000 people with dementia in Australia are still on antipsychotic medications, and that only ~10-14,000 of these people (20%) derive any real clinical benefit from this.[12]

3. What specific priority or initiatives can address any of the above deficits?

Dementia Australia strongly urges the MRFF Board to consider a sustained investment in dementia research, to be aligned with current and future MRFF Roadmap priorities.

Sustained investment in dementia research is urgently 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, their families and carers 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.

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11 Slote Morris Z, Wooding S, Grant J (2011) The answer is 17 years, what is the question: understanding time lags in translational research Journal of the Royal Society of Medicine, 104: 510-520,

12 Snowdon, J., Galanos, D., & Vaswani, D. (2011). A 2009 survey of psychotropic medication use in Sydney nursing homes. Medical Journal of Australia, 194(5), 270-1.

A commitment is needed to increased investment in dementia research over a 10-year period to achieve, say, a level of $80 million per annum 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 most effective way in which the Medical Research Future Fund can support dementia research in Australia is through additional funding for the NHMRC National Institute for Dementia Research (NNIDR), which was established in 2015 and which currently operates under the auspices of Dementia Australia. The NNIDR has created an effective network around Australia, with strong international links, and an effective working relationship with both the NHMRC (which provides research guidance and financial administration), and Dementia Australia (which is able to represent the views of those affected, their families and carers to the Institute). This additional funding could be used to:

- Continue to provide fellowships, development grants, and project grants to early and mid-career researchers on a competitive basis, to sustain and develop dementia research capacity in Australia.
- Provide a centralised national 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.
- 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, coordinated and internationally focused dementia research.
- Deliver funding to targeted priority-driven research aligned with the Strategy and priorities of the MRFF.

4. How can current research capacity, production and use within the health system be further strengthened through the MRFF?

Current research capacity and production can be strengthened by ensuring that all research funded through the MRFF can be measured and evaluated against the following key performance indicators:

- An agreed proportion of funding is disbursed as research grants with a demonstrably rigorous assessment process in place for grant funding.
- Proportion of research grants which lead to published research.
- Proportion of research grants which lead to changes to medical or health policy or services.
- Consumers have enhanced opportunities to participate in research, and take advantage of these opportunities, with high levels of consumer and researcher satisfaction with the co-research opportunities pursued.
- Both clinical and translational research are supported.
- A clearinghouse is established by the end of Year 1, and is actively utilised by researchers, consumers, and other stakeholders from Year 2 onwards.
- A standardised reference guide and approach to research in Australia is in place, and there is evidence that researchers have been assisted with recruitment of research participants. This is particularly significant for dementia research

- There is evidence of effective linkages and partnerships with stakeholders.

There is a focus on evaluation in all research trials and translational research.

Conclusion

Research into prevention, early intervention, treatment, and system responses will help equip Australia to meet the challenges that a steady increase in dementia prevalence will present to our primary health care, hospital, residential aged care, disability, and community care systems. We trust that the matters raised through our submission will be useful in helping the AMRAB determine funding priorities for the MRFF and welcome the opportunity to discuss our submission with you further.