

Professor Anne Kelso AO  
Chief Executive Officer, NHMRC  
GPO Box 1421  
CANBERRA ACT 2601

August 2016

Dear Professor Kelso

### **Alzheimer's Australia comments on Structural Review of NHMRC's Grants Program**

I am taking the opportunity on behalf of Alzheimer's Australia to offer some comments which are relevant to the current structural review of NHMRC's Grants Program. While Alzheimer's Australia does not wish to comment directly on the three alternative models for the future put forward in the consultation paper, we would like to make a few broader points in relation to the review.

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the second leading cause of death in Australia, and there is no cure.<sup>1</sup> Alzheimer's Australia represents and supports the more than 353,800 Australians living with dementia, and the more than one million family members and others involved in their care<sup>2</sup>. Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information. We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

Alzheimer's Australia congratulates the NHMRC for its initiative in undertaking this very significant and timely review. Given the current pressures on research grant funding and the high level of competition for grants, we strongly support the need for reforms to reduce the resources required for grant applications and review, to increase opportunities for talented researchers at all stages, and to encourage creativity, innovation, and flexibility.

While we understand the review is not considering research priorities, we trust that the reforms which result from the review will not have a detrimental effect on funding for, and collaborations in, dementia research. Research into prevention, early intervention, treatment, and system responses will help us find ways to improve the lives of people with dementia and their carers. It will also help equip Australia to meet the massive challenges increasing dementia prevalence will present to our primary health care, hospital, residential aged care, disability, and community care systems.

---

<sup>1</sup> Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013*: Cat no. 3303.0

<sup>2</sup> Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

**Alzheimer's Australia Inc.**

AMA House, Level 1, 42 Macquarie Street, Barton ACT 2600

**Postal Address:** PO Box 4194, Kingston ACT 2604

T: 02 6278 8900

Alzheimer's Australia ABN 79625582771



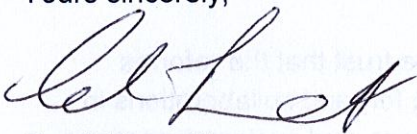
As you would be aware, funding for dementia research in Australia lags behind that of other national health priority areas. This has been addressed to an extent through the Government's Boosting Dementia Research initiative, and excellent work is underway including through the NHMRC's National Institute for Dementia Research (NNIDR). A new collective approach is being developed, which builds on previous partnership work involving our organisation and others, through the NNIDR, the NHMRC Cognitive Decline Partnership Centre, and the Dementia Collaborative Research Centres. Alzheimer's Australia and its national research foundation, the Alzheimer's Australia Dementia Research Foundation, are working together with these bodies in a collaboration which will be at the forefront of redefining our approach to dementia research in Australia. We trust that the changes which result from the structural review of the NHMRC's Grants Program will support the continued building of capacity and collaborations in dementia research.

We would also like to highlight the importance of ensuring that the consumer voice is at the forefront in developing health and medical research strategies. As you will be aware, involving consumers in research at all levels supports research rigour, helps to ensure the relevance and benefit of the research for consumers, and helps to improve dissemination and uptake of research findings. There are already some good models for consumer engagement in developing research strategies in Australia. For example, in the case of dementia, Alzheimer's Australia with support from the Dementia Collaborative Research Centres has developed a strong consumer network facilitating active consumer involvement in a range of research programs and initiatives including the Cognitive Decline Partnership Centre. In the case of cancer, we applaud Cancer Australia's work to develop a consumer engagement strategy and a consumer involvement toolkit for researchers; and its work to develop consumer expertise and capacity including with regard to clinical trials, through its Consumer Learning website.

Meaningful consumer involvement in all aspects of health and medical research is vital, and Alzheimer's Australia urges that the structural review consider ways in which consumer engagement can form a strong foundation for the NHMRC's Grants Program going forward.

Thank you for considering these comments, which I hope are helpful in your deliberations.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Carol Bennett', with a stylized flourish at the end.

**Carol Bennett**  
Chief Executive Officer  
Alzheimer's Australia