



Submission No. 067

mal (Dementia)

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Parliament of Australia
House of Representatives
Standing Committee on Health and Ageing
PO Box 6021
Parliament House
Canberra, ACT 2600

RE: Inquiry into Dementia: Early Diagnosis and Intervention

To the Standing Committee on Health and Ageing:

Thank you for the invitation to contribute to the Parliamentary Inquiry into *Dementia: Early Diagnosis and Intervention*. As the leading professional body supporting ageing research, the Australian Association of Gerontology (AAG) believes that building a robust evidence base in ageing research is essential to ensuring the health and wellbeing of older Australians, both now and in the future. With the anticipated ageing of Australia's population that will see up to a quarter of Australians aged 65 or over by 2050, it is important that we identify the health and medical challenges associated with an ageing population through appropriate multidisciplinary ageing research, including the impact of diseases such as dementia that increase in prevalence with age, as well as focus on the translation of research into policy and practice with the aim of best practice outcomes to improve the life of older Australians.

Within this context, it was noted that the terms of reference for the Inquiry acknowledged that the number of people with dementia is predicted to double over the next 20 years. While the AAG was pleased to see the Australian Government commit \$268.4 million to address dementia under the *Living Longer, Living Better* aged care reform package, including improved hospital and primary care, and reducing the time between symptoms and diagnosis, there was no mention of funding for dementia research. In order to understand how early diagnosis and intervention can improve quality of life and assist people with dementia to remain independent for as long as possible, and increase opportunities for continued social engagement and community participation for people with dementia, it is critical to invest in research that will provide a robust evidence base for policy makers and practitioners to deliver programs of benefit to older people with dementia and their carers.

While programs such as the Australian Government's *Ageing Well, Ageing Productively* Research Program have been useful in terms of advancing an ageing research agenda, a broader, more structured ageing research program that promotes collaborative, cross-disciplinary research and supports skills development and career opportunities for emerging researchers is required to ensure that the research community has the capacity to keep pace with the rapid changes expected of an ageing population, and the growing number of people expected to be diagnosed with dementia.

This submission will focus on the six key areas of: i) funding and capacity for ageing research; ii) translating research into policy and practice; iii) career opportunities for ageing researchers; iv) developing a national ageing research agenda; v) the contributions of ageing research networks; and, vi) aged care data.



Funding and Capacity for Ageing Research

Increased funding for ageing research, including dementia research, is essential if Australia is to develop the evidence-base required for the development and implementation of effective and efficient dementia care services that allow people to remain independent for as long as possible, promote social engagement for people with dementia, and help people with dementia and their carers plan for the future. In particular, the Committee should consider:

- 1) Investigator driven research funded by major nationally competitive grants schemes through the National Health and Medical Research Council (NHMRC) and the Australian Research Council (ARC). These schemes enable innovative, rigorous and novel research into biological, behavioural and social aspects of dementia. Such research is important for developing new approaches to dementia specific aged care programs and improving the lives of older people with dementia.
- 2) Targeted research funded through nationally competitive grants schemes and funding rounds. These processes also allow for rigorous and novel research addressing areas of identified priority. Such targeted approaches help to ensure more comprehensive knowledge generation in areas of specific need and importance in dementia.

Furthermore, very little is known about best practices for caring for older people with dementia, and, in particular, people with special needs, such as people with dementia from GLBTI backgrounds or culturally and linguistically diverse backgrounds. Moreover, there is also almost no information available on the health of older Indigenous peoples with dementia, with the exception of a few specific studies in selected communities, such as the Kimberley Indigenous Cognitive Assessment study, the Lungurra Ngoora service model project, and the Koori Growing Old Well study.

In 2004, the NHMRC and the ARC did call for submissions to advise and refine research themes in the area of *Ageing Well, Ageing Productively*, reflecting national research priorities. These grants were awarded to six projects, including the 'Gene-environment interaction in healthy brain ageing and age related neurodegeneration', which considered the concordance rate for mild cognitive impairment and dementia in twins, and the 'Dynamic Analyses to Optimize Ageing (DYOPTA)' project, which focused on dementia and cognition in relation to compressing morbidity and optimising ageing. A second round of *Ageing Well, Ageing Productively* research grants, or some similar research program targeted towards ageing research, has not been announced. The AAG believes that a second round of *Ageing Well, Ageing Productively* research grants would add considerable depth to the evidence-base and be of great benefit to policy makers dealing with the complexities of an ageing population.

Translating Research into Policy and Practice

Presently, there is an overemphasis by the NHMRC and other funding bodies on publications being the primary outcome of research, rather than a focus on practical implementation of research. To ensure that research results in effective outcomes to improve the lives of older Australians with



dementia, there is a need for translating ageing research into meaningful policy and practice outcomes. This requires funding to be built into the grant application process to allow researchers to engage with relevant stakeholders, including consumers, service providers, practitioners, researchers and policy makers, to identify key areas of research and models of best practice, as well as incorporating mechanisms for disseminating and translating research findings effectively to increase the uptake and application of knowledge by policy makers and health care professionals.

Moreover, where new models of practice have been shown to be effective in research studies, which by their very nature are conducted in very controlled situations and limited service contexts, they should be rolled out gradually accompanied by rigorous evaluation, the results of which are then used to progressively improve the model. This would ensure that applied research is able to be effectively translated into best practice outcomes.

Translational research is itself an area worthy of substantive investment and scholarly activity. Dementia research needs to focus on the unacceptable gap between our unprecedented knowledge of the disease and the implementation of that knowledge. Directed and innovative research is needed to analyse the causes of this situation and to point toward solutions at the global and local levels, both within and outside the health and aged care sector.

To support the formative evaluation of new models of practice, aged care service providers should be encouraged by way of funding incentives to attract high-calibre researchers to undertake focussed and relevant research to improve systems and services for older people living with dementia. Working directly with the service sectors would allow researchers to have a more in-depth understanding of the needs of older people with dementia, as well as the research needs and specialist research methods for service improvement and care delivery.

Translational research is also important for education and training in relation to dementia. In order to ensure that health, aged and community care staff are able to deliver the best possible care for people with dementia, they need the appropriate training and education backed by the latest evidence in dementia care.

Career Opportunities for Ageing Researchers

In addition to the need for more accessible and targeted research funding for dementia, there is an urgent need to build Australia's workforce capacity in dementia research. A strong research and development focus, supporting skills development and career opportunities for emerging researchers in dementia will be a national resource in addressing the health and medical needs of the ageing population over the coming decades. For successful research outcomes, it will be necessary to harness all the existing expertise as well as promoting the development of additional expertise.

Importantly, as already indicated, this research capacity should be invested in both academic and service sectors and should facilitate effective collaborations, skill sharing and knowledge transfer.



Such partnerships ensure a well-educated ageing research workforce that is capable of undertaking timely and relevant dementia research around the needs of an ageing population.

National Ageing Research Agenda

The paucity of evidence on particular topics relevant to the health and wellbeing of older Australians was noted in the Productivity Commission's recent report on "Caring for Older Australians", as was the need for stronger research and a better evidence base to inform policies and test and evaluate programs and proposed reforms. However, the report did not recommend a mechanism for prioritising research to ensure that funding can be directed in a timely fashion to addressing the questions that government, policy makers, care providers, care professionals, older people and the community more generally, agree are the most critical.

Maintaining health as we age is an important social and economic objective. The goal of ageing well is to increase the probability that people will remain physically, mentally and socially active, and to delay the onset and improve the management of chronic conditions, such as dementia. A research agenda will contribute to achieving this goal by setting the foundations for a robust evidence base to inform policy and practice outcomes.

The AAG believes the best mechanism for identifying critical areas of ageing research would be the development, and regular updating, of a National Ageing Research Agenda with broad consultation and input from all key stakeholders. Such an approach could build on the achievements of earlier strategies and government funded programs, including the Framework for an Australian Ageing Research Agenda, the ARC/NHMRC Research Network in Ageing Well, and the Ageing Well Ageing Productively Research Grants program, all of which were valuable in assisting to build a robust evidence-base, but which are no longer in effect and have not been replaced.

The AAG is currently working with the NHMRC to develop a National Ageing Research Agenda, which will include dementia specific research.

Ageing Research Networks

The capacity for dementia research is, however, not only invested in academic research centres. In recent years, many more provider organisations, having come to appreciate the value of research and wishing to contribute to the development of the research evidence-base, have employed researchers as permanent staff or as contractors to undertake specific projects or evaluations. While the AAG acknowledges the importance of independence in dementia related policy research and evaluation, there are also advantages to having an internal evaluator or internally driven research, for example: understanding of the service and program context; access to, and knowledge of, all potential data sources; and, a feeling of ownership of the process and hence the findings by the organisation. This latter fact is more likely to result in the findings being directly translated into organisational policy and practice.

The AAG supports the concept of organised networks of researchers and providers who can share knowledge and skills, and, with input from other key stakeholders such as older people themselves,



identify and conduct research that is most likely to lead to policy and practice change. The AAG believes that a national ongoing strategy for maintaining and enhancing our research capacity is required. The AAG has identified 19 collaborating research centres with expertise in ageing research. These centres employ high-profile researchers from across Australia with interests in biological, social, psychological, medical research. Together, the centres represent enormous potential for building a robust capacity for large-scale, multi-disciplinary research into dementia. What is needed now are the resources and organisational structure to enable the centres to work together more effectively to optimise Australia's ageing research potential.

Aged Care Data Sets

Improving access to aged care data sets is also an area that warrants further investigation. While the AAG is pleased with the Australian Government's recent announcement of the establishment of a centralised aged care data clearing house at the Australian Institute for Health and Ageing as part of its aged care reform package, *Living Longer, Living Better*, it is unclear how the AIHW will utilise and manage the data.

Moreover, while researchers will be grateful to have access to a central repository of aged care data, if there is little funding directed towards ageing research then the routine collection of data will be underutilised and unable to address critical questions concerning the effectiveness and efficiency of dementia specific aged care services. To ensure that the most is made from the substantial investment in collecting data, there is a need to invest in ageing research and the capacity of the ageing research sector.

Summary

In summary, ageing research must be a major focus when considering early diagnosis and intervention in relation to dementia, and as such should be supported by a dedicated and targeted funding stream that not only enables greater opportunities for collaborative, cross-disciplinary research, but also increases capacity in the sector by supporting skills development and career opportunities for researchers. Any research program will also need to have input from a wide range of stakeholders to ensure that research is policy and practice relevant; therefore, support for mechanisms encouraging multi-disciplinary research networks and the effective translation of research into policy and practice is also required.

On behalf of the AAG, thank you once again for the opportunity to contribute to the Inquiry into dementia. We look forward to seeing this important issue addressed by the Australian Government.

Yours sincerely,

Professor Julie Byles
President
Australian Association of Gerontology

Dr Tony Coles
National Executive Officer
Australian Association of Gerontology