

ALZHEIMER'S ATTACKS
AUSTRALIA ACTS
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2013-14
BUDGET SUBMISSION

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BUDGET SUBMISSION, 2013-14

INTRODUCTION

The *Tackling Dementia* measures announced by the Government in the *Living Longer. Living Better* aged care reform package lay the basis for better care of people with dementia. But they do not address the urgent need to reduce the number of people with dementia in the future.

This submission outlines a five-year package of funding that will build necessary capacity in the Australian dementia research sector. This will allow Australia to move towards a world where:

1. The onset of dementia is delayed by five years from an average age of 85 to an average age of 90;
2. One million fewer Australians develop dementia by mid-Century, and the number of people living with dementia in 2050 is reduced by one third;¹
3. People with dementia now and in the future have a better quality of life and receive better, evidence-based care.

To achieve these outcomes, a targeted investment of \$200 million over five years, starting with \$16.5m in 2013-14, is required to:

1. Build the capacity of the dementia research sector by attracting new researchers and enhancing research leadership and collaboration;
2. Support vital dementia research including priority-driven research that directly responds to policy and clinical evidence needs;
3. Effectively translate existing evidence into better health and aged care programs, services and policies for people with dementia; and
4. Establish necessary dementia research infrastructure.

Along with the \$20-30 million currently provided for dementia research through the NHMRC, this additional funding will bring the total investment in dementia research to a level comparable with other National Health Priority Areas on the basis of current and future disability burden and health care expenditure.² \$60 million per annum for dementia research is approximately 1% of the current cost of dementia care.³

Why is this required, and why now?

There are currently no treatments or interventions that can prevent, delay or reverse dementia. The major barriers to their development in Australia are the lack of research capacity, funding and infrastructure.

We are optimistic that an increased investment in dementia research will allow Australia to move towards a world without dementia over the next decade because:

1. Multiple strategies are currently being pursued to delay or reduce the risk of dementia, including therapies to neutralise the toxic effects of proteins in the brain, vaccination, stem cell therapies and gene therapy;
2. New medications designed to delay the progress of dementia in the brain are currently undergoing clinical trials;
3. New medical technologies are being developed to detect dementia years before symptoms emerge so that it will be possible to treat those most at risk;
4. We are beginning to understand the environmental, behavioural and genetic risk factors that may help people reduce their risk of developing dementia.

Australia has the potential to take advantage of these scientific developments in a way that will reduce the burden of dementia and improve the quality of life for people living with the condition.

However, this will only be achieved with a substantial and focussed research effort. Despite boasting some of the world's leading scientists and pioneering research programs in neuroimaging, immunotherapy and risk reduction, Australia's dementia research sector is currently underfunded in comparison to other National Health Priority Areas,⁴ and lacks the capacity to compete for limited funding with longer established disease research areas.

RECOMMENDATIONS

Alzheimer's Australia recommends additional funding of \$40 million per annum for five years should be committed as follows:

Capacity Development		
1.	Expand Australia's dementia research capacity by supporting 150 new and emerging dementia researchers and future research leaders through the NHMRC and the ARC;	\$58.25 million
2.	Build national leadership in dementia research by establishing 5 new senior research leadership positions through the NHMRC	\$18.75 million
3.	Promote collaboration and information exchange among Australian dementia researchers through a virtual research network	\$3 million
Research Funding		
4.	Allocate funding for investigator-initiated dementia research projects and programs through the NHMRC and the Department of Health and Ageing's Flexible Funds.	\$50 million
5.	Establish a fund to allow the Government to commission priority-driven research that responds directly to dementia policy, clinical and care information and evidence needs	\$40 million
Evidence Translation		
6.	Establish a dementia research clearinghouse to provide rapid access to clinically relevant research	\$5 million
Research Infrastructure		
7.	Invest in vital dementia research infrastructure in partnership with State and Territory Governments, research institutes and philanthropic bodies.	\$22.5 million
8.	Establish a national dementia research registry and data repository to facilitate recruitment of research participants and research access to pooled data from publicly funded research.	\$2.5 million

A detailed budget proposal is included in the Appendix to this submission. Expenditure in respect of these commitments would be spread over 9 years.

PRIORITY AREA I – CAPACITY BUILDING

Issue

Dementia research is underfunded in comparison to other health and medical research areas in terms of total dollars and in comparison to disability burden and health system costs. In 2012-13 the National Health and Medical Research Council (NHMRC) allocated \$21.5m to dementia research compared to \$162.4m for cancer, \$93.6m for cardiovascular disease, \$63m for diabetes, and \$55.1m for mental health.⁵ Dementia, which ranks second behind cardio-vascular disease in terms of health system expenditure, and fourth overall in terms of disability burden, received just 5% of almost \$400m funding allocated to research on these five diseases.

Current Situation

Dementia research in Australia is underfunded and has been falling behind most other chronic disease research areas for the past decade⁴ (Figure 1).

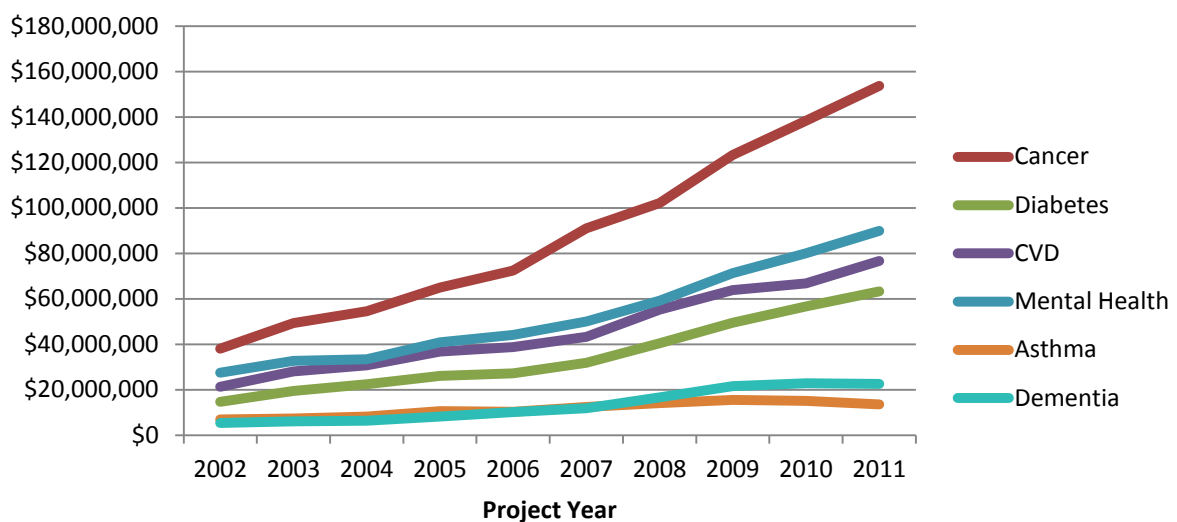


Figure 1. NHMRC Research Expenditure by Chronic Disease: 2002-2011

The reason for this is that the dementia research sector is smaller and less developed than comparable health research areas, and is not growing quickly enough to be able to compete on an equal basis in Australia's competitive research funding environment.⁴

To redress this situation, the dementia research sector needs to attract new researchers into the field at early and mid-career levels, and to establish a cohort of future research leaders. Figure 2 shows that the NHMRC supported just 56 new dementia researchers over the past decade compared to over 700 cancer researchers and almost 500 in cardiovascular disease. The dementia research

sector will never be able to compete unless action is taken to expand dementia research capacity now.

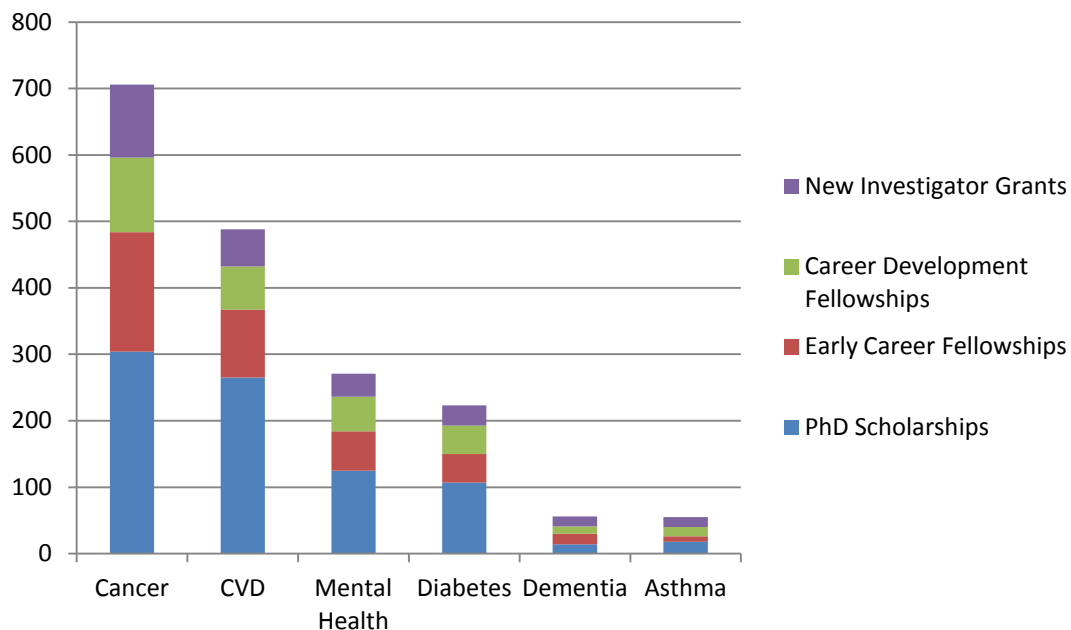


Figure 2. NHMRC Early Career Support (total number of scholarships, grants and fellowships) by Chronic Disease: 2002-2011.

Alzheimer’s Australia is giving priority to building dementia research capacity. In 2013, our Research Foundation will advertise 28 scholarships, fellowships and seeding grants for new and early career dementia researchers at a total value of almost \$2.5m. However, this is only a small fraction of what is required.

Outcomes

A significant increase in the number of new students, early and mid-career dementia researchers and future research leaders over the next five years and a number of new high-profile research leadership positions to help support them. This will help to ensure that the dementia research sector is of sufficient size and capacity to operate effectively in Australia’s competitive research funding environment, allowing our best and brightest researchers to undertake their vital research alongside other equally important health and medical research areas. Funding for a virtual dementia research network will also promote increased collaboration and information exchange between Australian dementia researchers.

Action

1. Provide \$58.25 million over 5 years to expand Australia's dementia research capacity by supporting 150 new and emerging dementia researchers and future research leaders through the NHMRC and the ARC. Specifically:
 - 50 new NHMRC Postgraduate Scholarships
 - 50 new NHMRC Early Career Research Fellowships
 - 25 new NHMRC Career Development Fellowships
 - 25 new ARC Future Fellowships
2. Provide \$18.75 million over five years to build national leadership in dementia research by establishing 5 new senior research leadership positions (equivalent to the NHMRC's John Cade Mental Health Fellowships) through the NHMRC;
3. Provide \$3 million over five years to promote collaboration and information exchange among Australian dementia researchers through a virtual research network.

PRIORITY AREA 2 - RESEARCH FUNDING

Issue

The ongoing lack of capacity in the dementia research sector has meant that vital research into new treatments, interventions and care has not been undertaken. As with other health research areas, there has also been a lack of emphasis given to funding priority driven research, resulting in failures and inefficiencies in the translation of health and medical research outcomes into healthcare practice.

Current Situation

The McKeon Review of Health and Medical Research in Australia has recognised the need to strike a better balance between funding for bottom-up and top-down research, and recommended that this rebalancing start with an allocation of 10-15% of the NHMRC's Medical Research Endowment Account towards priority driven research across 8-10 National Health Research Priority Areas.⁶

Outcome

Increased funding to support new Australian research initiated by a growing research sector and a funding pool to allow the Australian Government to commission priority-driven research that responds directly to the information and evidence needs of dementia policy makers and clinicians.

Action

4. Allocate \$50 million over five years for investigator-initiated dementia research projects and programs through the NHMRC and the Department of Health and Ageing's Flexible Funds.
5. Provide \$40 million over five years to establish a fund that will allow the Australian Government to commission priority-driven research that responds directly to dementia policy, clinical and care information and evidence needs.

PRIORITY AREA 3 - TRANSLATING EVIDENCE INTO PRACTICE

Issue

In order to improve health outcomes, health and medical research findings need to be effectively translated into healthcare policy and practice. In dementia, as in many areas of healthcare, this translation fails to happen, or happens unacceptably slowly.

As a consequence, it has been estimated that 86% of health and medical research never reaches healthcare practice, and that it takes an average of 15.6 years for the remaining 14% to filter down from academic publication into mainstream practice.⁷ These failures of evidence translation contribute to the fact that approximately 30-40% of Australian healthcare is inconsistent with best-practice clinical guidelines,⁸ and that as much as 20-25% of all healthcare services provided are either unnecessary or actively detrimental to patient wellbeing.⁹

Current Situation

There is a significant discrepancy between established scientific evidence and mainstream healthcare practice in many areas of dementia care. For example:

- up to 50% of people with dementia are never diagnosed, despite the widespread availability of clear guidelines and validated assessment measures;
- best-practice person-centred care is not routinely provided despite substantial evidence establishing the benefits;
- many people with dementia die in hospitals without access to palliative care at significant cost to the healthcare system and detriment to patient and family wellbeing; and
- physical and chemical restraints are overused in residential aged care causing many thousands of avoidable deaths each year.¹⁰

The Australian Government has made a commendable effort to improve the translation of existing evidence into better care through initiatives including the Dementia Collaborative Research Centres, the Dementia Training Studies Centres and the NHMRC Partnership Centre on Cognitive Decline.

Alzheimer's Australia has also been working to address this issue through the National Quality Dementia Care Initiative. This \$3.3 million initiative aims to find and implement on a national scale the best available evidence relating to problems and issues in dementia care that have been prioritised by consumers. Since its establishment in 2010, the Initiative and the national 25-member Consumer Dementia Research Network who are driving it have supported eight innovative

projects that are actively improving the quality of dementia care through translation of evidence in every state and territory of Australia.

This world-leading program commenced with support from philanthropic sources and from the Dementia Collaborative Research Centres, and has developed the infrastructure, networks and processes to continue driving real improvements on a national level with small amounts of ongoing funding. Alzheimer's Australia has made an application to the Department of Health and Ageing's Aged Care and Service Improvement Healthy Ageing Grants Fund for funding to continue this important program.

Outcome

Targeted funding for translation of existing evidence into better dementia care practice on a national scale will result in higher-quality and more cost-effective dementia care services. Funding to establish a national dementia research clearinghouse similar to the *CareSearch Palliative Care Knowledge Network* will give consumers, dementia policy makers, clinicians and dementia care workers and managers a central point of access to the best available research evidence on various aspects of dementia care.

Action

6. Provide \$5 million over five years establish a dementia research clearinghouse to provide rapid access to clinically relevant research

PRIORITY AREA 4 - RESEARCH INFRASTRUCTURE

Issue

Dementia research is advancing rapidly thanks in large part to the availability of new biomedical technologies. In order to remain at the leading edge of this research and ensure the earliest access for Australians to new interventions and treatments, it is essential that Australia invests now in next generation research infrastructure. In order to facilitate patient recruitment into high-priority clinical research and capitalise on data from existing publicly funded research, Australia also needs a national dementia research registry and data repository.

Current Situation

The most rapid international advances in dementia research are currently occurring in the fields of biomarkers, genomics and proteomics, and bioinformatics. For example, Positron Emission Tomography (PET) scanning using specialised radioisotopes is able to detect the accumulation of the toxic amyloid beta protein in the brains of people with Alzheimer's disease as much as a decade before the first functional symptoms appear. However, facilities are currently only available in Melbourne and Perth. In order to capitalise on emerging trends and ensure that Australia maintains its position as a leader in dementia research in the future, ongoing investment in this technology is required.

Outcome

Improved dementia research infrastructure that will allow Australia to continue leading the world in specialised and potentially commercially valuable dementia research areas such as PET scanning, and a national research registry and data repository that will facilitate patient recruitment into high-priority clinical trials, and allow researchers easier access to pooled data from publicly funded research. This infrastructure will give Australians with dementia first access to valuable new treatments and interventions as research participants and as clinical patients in the future.

Action

7. Invest \$22.5 million over five years in vital dementia research infrastructure in partnership with State and Territory Governments, research institutes and philanthropic bodies.
8. Invest \$2.5 million over five years to establish and support a national dementia research registry and data repository.

APPENDIX

Additional Funding 2013-14 to 2017-18

Additional Funding Allocation (\$ million allocation)						
	2013-14	2014-15	2015-16	2016-17	2017-18	Total
Capacity Development	16	16	16	16	16	80
• 50 Postgraduate Scholarships	0.75	0.75	0.75	0.75	0.75	3.75
• 50 Early Career Fellowships	3.2	3.2	3.2	3.2	3.2	16
• 25 Career Development Fellowships	2.2	2.2	2.2	2.2	2.2	11
• 25 Future Fellowships	5.5	5.5	5.5	5.5	5.5	27.5
• 5 Research Leadership positions	3.75	3.75	3.75	3.75	3.75	18.75
• National Research Network	0.6	0.6	0.6	0.6	0.6	3
Priority Driven Research Funding	18	18	18	18	18	90
• Dementia Research Funding	10	10	10	10	10	50
• Priority Driven Research Fund	8	8	8	8	8	40
Evidence Translation	1	1	1	1	1	5
• Research Clearinghouse	1	1	1	1	1	5
Research Infrastructure	5	5	5	5	5	25
• Infrastructure Investment	4.5	4.5	4.5	4.5	4.5	22.5
• Research registry and data repository	0.5	0.5	0.5	0.5	0.5	2.5
Total	40	40	40	40	40	200

If implemented, this proposal would require actual expenditure over 9 years (3-5 year terms for scholarships and fellowships, and 2-3 years for research projects). The additional funding required in 2013-14 would be just over \$16.5 million.

Financial Year	Additional Expenditure (\$ millions)
2013-14	16.55
2014-15	26.50
2015-16	34.95
2016-17	43.15
2017-18	45.00
2018-19	18.45
2019-20	8.50
2020-21	5.05
2021-22	1.85
Total	200

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