
Australian Dementia Research: current status, future directions?

A report for Alzheimer's Australia
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FOREWORD

Bipartisan support for the *Dementia Initiative – Making Dementia a National Health Priority* has provided a welcome and increased focus at the national level on a number of issues, including research.

The important initiatives taken in respect of funding for dementia grants and the three Dementia Collaborative Research Centres are a sign of national recognition that dementia research is an important part of any strategy in addressing the dementia epidemic.

Important though the initiatives of the last few years have been, it remains the case that dementia research is the poor cousin in medical research – and research on dementia care an even poorer cousin. In commissioning this report Alzheimer's Australia has set out to demonstrate that on any objective basis, dementia research is under-funded. The impact of the dementia epidemic, whether on public health costs, social costs of families and carers, or the disability burden of the individual, suggests that Australia needs to make a more substantial investment for the future.

Alzheimer's Australia would like to thank the JO & JR Wicking Trust for providing the funding for this research and to thank the authors of this report, Lee-Fay Low, Lisa Gomes and Henry Brodaty, for putting together what we hope is a useful document for policy makers and those responsible for setting priorities in respect of the Australian medical research effort.

I would also like to thank the Members of the Alzheimer's Australia Research Medical and Scientific Panel for their comments on the draft of the Report.



Marc Budge

President
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EXECUTIVE SUMMARY

The dementia epidemic is here and has significant impact on health care and social costs in the wider community. In 2007 there were an estimated 220,050 people with dementia; by 2030 this figure will have more than doubled to 465,460 and by 2050 the figure will reach 731,030 people. Dementia is the chronic disease that is projected to show the greatest increase in disease burden by 2023.

The direct cost to the health and care system of dementia is projected to rise to \$8.2 billion by 2022-23.

Investment in dementia research, whether in cause, cure or care, is a key strategy for addressing the epidemic. Historically, medical research in Australia has produced returns of \$5 for every \$1 spent.

Economic modelling has shown that if the onset of dementia could be delayed by 5 years there would be significant savings to the health and care system.

Australian researchers have contributed significantly to the global effort in dementia research and are world leaders in research on the aetiology of dementia, epidemiology, carers, and dementia management.

Relative to current disease burden and current direct cost of care, dementia research in Australia is significantly under-funded. Annual expenditure on dementia research is currently \$12.8 million (0.57% of the total direct cost of dementia). In comparison with other major diseases, this is about:

- 50% of research funding for cancer, relative to current disease burden.
- 30% of research funding for cardiovascular disease, relative to current direct cost of care.
- 20% of research funding for cancer and diabetes, relative to current direct cost of care.
- 5% of current research funding for cancer, relative to predicted direct cost of care in 2023.

Recommendations:

- Annual Australian expenditure on dementia research should be increased three-fold to \$36 million. This would bring it more into line with expenditure on cardiovascular and cancer research in relation to direct costs.
- Investment in dementia research should be maintained at about 1.5% of the direct cost of dementia and increase corresponding to costs over time.
- Dementia should be included as a National Health Priority Area by the National Health and Medical Research Council (NHMRC).
- Priority should be given to research relating to dementia service delivery and prevention as well as to translating dementia research findings into practice.

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INTRODUCTION

Dementia is the umbrella term for a heterogeneous group of disorders characterised by loss of memory and impairment to thinking and problem-solving capabilities. Dementia causes progressive neurodegeneration leading eventually to death. Common types of dementia are Alzheimer's disease (50-70% of all dementia cases), vascular dementia (10-20% of cases), Lewy body dementia (10-20% of cases), and frontotemporal dementia (2% of cases).

Many cases have a mixture of pathologies. Subtle changes in cognition and function can occur up to ten years before symptoms are apparent [1, 2]. The median survival time after symptom onset is 4.5 years [3]; this varies with age and dementia subtype.

Australia has an ageing population as a result of the almost complete elimination of deaths from childhood infectious diseases; reductions in mortality from chronic systemic diseases, such as cardiovascular disease, cancer, and respiratory disorders; and the post WWII baby boom (1946-1965) [4]. Age is the greatest risk factor for dementia [5], hence there are increasing numbers of persons with dementia. In 2007 there were an estimated 220,050 people with dementia representing 1.06% of the total population [6]. By 2030 this figure will have more than doubled to 465,460 representing 1.88% of the population and by 2050 the figure will reach 731,030 or 2.77% of the population [6].

In 2003 dementia was the 11th largest cause of disease burden in Australia; by 2023 it will be the 4th largest cause [7]. Access Economics estimated that in 2002 the total cost of dementia was AUD 6.6 billion [8]. Using different parameters the Australian Institute of Health and Welfare estimated that in 2003 dementia direct costs were AUD 1.4 billion and this is projected to increase to AUD 8.2 billion by 2022-23 [7]. Similarly, the number of persons with dementia will increase in the Asia Pacific region from 13.7 million people with dementia in 2005 to 23.7 million in 2020, of whom 9.5 million will come from China and 5.5 million from India [9]. The projected financial and societal costs of the dementia epidemic are very high [8, 10] and these may be underestimates as the baby boomer generation is will demand more medical and health services than previous generations [11].

The neuropathological changes characteristic of Alzheimer's disease, beta-amyloid plaques and neurofibrillary tangles, were first described by Alois Alzheimer in 1906. Research in dementia was limited until the 1980s, but since then there have been many developments [12]. For instance, we have a better understanding of the molecular and cellular changes that occur in the various dementias, leading to the development of five drug treatments that slow the worsening of symptoms of Alzheimer's disease [13]. Growth of new neurons and neuronal connections have been observed in adult human brains, suggesting that lost neurons may be replaced [14]. A large number of modifiable risk factors for dementia have been identified, including low education, head injury, high blood pressure and physical and mental inactivity [15]. There have also been developments in neuropsychological testing and neuroimaging, leading to earlier diagnosis [16].

Understanding the negative consequences of behavioural and psychological symptoms of dementia has led to the development of pharmaceutical and non-pharmaceutical treatments [17]. Recognition of the important role of families in the care of persons with dementia, and the stressors that accompany this role, have led to improvements in support and services for carers [18, 19].

But fundamental questions remain [12]:

- There is no consensus on the causes of Alzheimer's disease, Lewy body disease, or frontotemporal dementia.
- The epidemiology of dementia at the extremes of age (i.e. in the young and in the

very old); persons from culturally and linguistically diverse (CALD) backgrounds; Australian Aboriginal and Torres Strait Islanders; and persons with developmental delay, has not been fully described.

- There is only consistent evidence for one susceptibility gene for non-familial forms of dementia. It is likely that there are others.
- There are no dementia treatments that reverse or halt any form of the disease.
- There is no simple, accurate method for diagnosing very early dementia.
- It is not known which, when, and by how much, risk factors need to be modified in order to delay or prevent dementia.
- The best models to meet the care needs of persons with dementia, including the role of community care, have not been identified to maximise quality-of-life and cost-effectiveness.
- People with dementia rarely have a voice. We need to advance our knowledge of their experiences, perspectives, and ways of communicating at different stages of the disease.
- It is not clear how to best train nurses, doctors, allied health and other paid carers, in supporting persons with dementia and minimising its impact on these care professionals.
- We know very little about how to translate the best evidence into practice.

Australia is a small country with limited resources and needs to conduct priority-driven research [20]. Investment in Australian medical research and development has historically produced excellent returns of up to \$5 for every \$1 invested [21]. This decade is crucial in responding to the dementia epidemic because commencement of a research program and implementation of the outcomes in policy and practice. In 2005 dementia was made a National Health Priority by the Australian Government. Sixteen million dollars was allocated for dementia research project grants and \$7 million was awarded over three years for three Dementia Collaborative Research Centres (DCRCs). The *Dementia, A National Health Priority Initiative* is being evaluated by the LAMA (LaTrobe University, Access Economics, Monash University and Aged Care Solutions) consortium. Continuity of funding is not guaranteed.

Is Australia investing enough in dementia research? What research areas should we be targeting?

The National Framework for Action on Dementia 2006-2010 states that identification of key areas for national research is an immediate priority. The Federal-Government-commissioned Dementia Research Mapping project reviewed the international dementia literature and identified numerous gaps in all areas of dementia research [12], but the purview of the project did not include examining the state of Australian dementia research.

The aims of this report are:

- 1) To take stock of recent Australian dementia research to identify areas of strength and weakness; and,
- 2) To compare Australian dementia research funding levels with levels of research funding for other chronic diseases, and to levels of dementia research funding in the USA, UK, and Canada.

METHODOLOGY

Australian journal publications

Australian journal publications on dementia between 2005 and 2007 were obtained by searching Medline, PsychInfo, Cinahl, PubMed and Scopus databases on 3rd January 2008 for the keywords 'dementia' or 'Alzheimer' or 'mild cognitive impairment'. Australian journal publications were defined as having been conducted with an Australian sample (even if none of the authors were based in Australia at time of publication) or as having at least one author based at an Australian institute.

Book reviews, editorial introductions, *errata*, overviews of conference proceedings and abstracts were excluded from the publications reviewed.

Journal articles were classified according to Research Activity Codes developed by the UK Clinical Research Collaboration [22]. The Clinical Research Collaboration based the development of these codes on the Common Scientific Outlines of the International Cancer Research Partners, with input from industry and the Association of Medical Research Charities. They were refined after pilot studies. The Research Activity Codes categories are:

- a) Underpinning research
- b) Aetiology
- c) Prevention of disease and conditions, and promotion of well-being
- d) Detection, screening and diagnosis
- e) Development of treatments and therapeutic interventions
- f) Evaluation of treatments and therapeutic interventions
- g) Management of disease and conditions
- h) Health and social care services research

We added the category 'Carers' to refer to research relating specifically to carers of persons with dementia. One author (LG) classified all the journal articles according to the descriptors provided for these codes. A second author (LFL) independently classified 30 randomly selected articles; the inter-rater reliability was 0.8. Journal articles presenting research on beta-amyloid, tau proteins, and risk factors were coded under b) Aetiology.

In addition, journal articles were classified according to dementia type (dementia in general, Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, or other). Articles reporting on dementia in the special groups identified by the *Dementia, A National Health Priority Initiative*, were recorded. These special groups are: persons with younger onset dementia; persons from culturally and linguistically diverse (CALD) backgrounds; Aboriginal and Torres Strait Islanders; persons with developmental delay; and persons from rural and regional communities. The type of article (e.g. original research, review or other), and the types of research subjects (e.g. human participants, animals or cells), were also recorded.

The Elsevier Scopus database was searched on 14th May 2008 for all publications containing the keywords 'dementia' or 'Alzheimer' or 'mild cognitive impairment'. The number of Australian and all publications were tallied by year and the number of publications with 20 or more citations between 2002-2007 were collated.

Australian clinical trials

A search of the Australian Clinical Trials register, the Australian Consortium for Clinical Cognitive Research (AC4R) website, the US-hosted Clinical Trials Register, and Alzforum websites was undertaken for information on current Australian clinical trials relating to dementia. Information on the title of the trial, chief investigator, chief investigator's research institution, sample size, type of dementia studied, and whether the trial was single or multi-site, were recorded for each clinical trial. Where it was unclear whether the trial was conducted in Australia, the chief investigator was contacted.

Australian organisations conducting dementia research

A list of Australian organisations that had published dementia research between 2005 and 2007 or were conducting clinical trials (except for pharmaceutical companies), was drawn up.

Historic research strengths

Information on Australian historic research strengths in dementia were collected by surveying the Alzheimer's Australia Scientific and Medical Panel and its international contacts.

Australian research funding

Data on Australian Government research funding for dementia and other chronic diseases (cancer, cardiovascular disease, diabetes, mental illness, and chronic respiratory disease) between 2002 and 2007 were obtained from datasets on funded grants from the NHMRC and ARC websites. It is notable that the NHMRC includes grants that address several disease areas under more than one area of disease, such that the total of funding by disease area may exceed total NHMRC funding. State and territory government research funding data were gathered by searching state government and state health department websites for published reports and lists of funded research projects. The Medical Research Officer of the Health Department was contacted if the information was not publicly available.

A list of not-for-profit and for-profit organisations, which fund research into the disease areas of interest, was drawn up through a general internet search and search of the SPIN funding opportunities database. Data on the amount of research funding from each organisation on the list were then compiled from lists of research grants awarded, annual reports, and newsletters. Organisations were contacted for additional information.

The title and description (when available) of grants were used to categorise them by chronic disease.

The source of information and amount of funding for specific Australian organisations are listed in Appendix A (available online at www.alzheimers.org.au).

Burden of disease and cost of care

Comparing research funding levels between chronic diseases is complex and inexact. To maximise comparability information for a data type was drawn from a single source whenever possible. Information on the current burden of disease for dementia and other chronic diseases was obtained from the most recent Australian burden of disease report [7]. The author of this report was contacted to obtain details about the projected burden of these diseases (Stephen Beggs, 2007, personal communication).

The current and projected direct costs of care for dementia and other chronic diseases were identified from the published literature. Information on the indirect cost of care was also collected from published literature, when available. Indirect costs of mental illness and chronic respiratory disease were estimated using the published ratio of indirect and direct costs. The amount of research funding relative to direct costs of care, and disease burden in disability adjusted life years (DALYs) was calculated for each chronic disease.

International funding

A list of the major government departments responsible for funding medical research in the US, the UK, and Canada was compiled from published reports and through correspondence with Alzheimer's organisations in those countries. The websites of these departments were then searched for data sets, published reports and other documents reporting government spending on dementia research.

The major Alzheimer's organisation(s) in the US, the UK, and Canada, who provide dementia research funding, were identified. The Wellcome Trust was also identified as a major source of research funding in the UK and included in the funding data. The websites of these organisations were searched for current and past amounts of funding awarded for dementia research and organisations were contacted when necessary.

The sources of information and the amount of funding for international organisations are listed in Appendix B (available online at www.alzheimers.org.au).

RESULTS

Australian dementia research

Australian dementia publications

Australian researchers are well-represented and well-cited in dementia research. The Scopus database showed that up to the 14th May 2008 2.3% of all dementia publications had Australian authors. Between 2002 and 2007 14.2% of Australian dementia publications had been cited 20 or more times compared with 13.0% of the worldwide dementia literature. The number of Australian dementia publications is growing with the increasing global trend (see Figure 1).

FIGURE 1 Dementia publications by year from Australia and the world 1964 - 2007

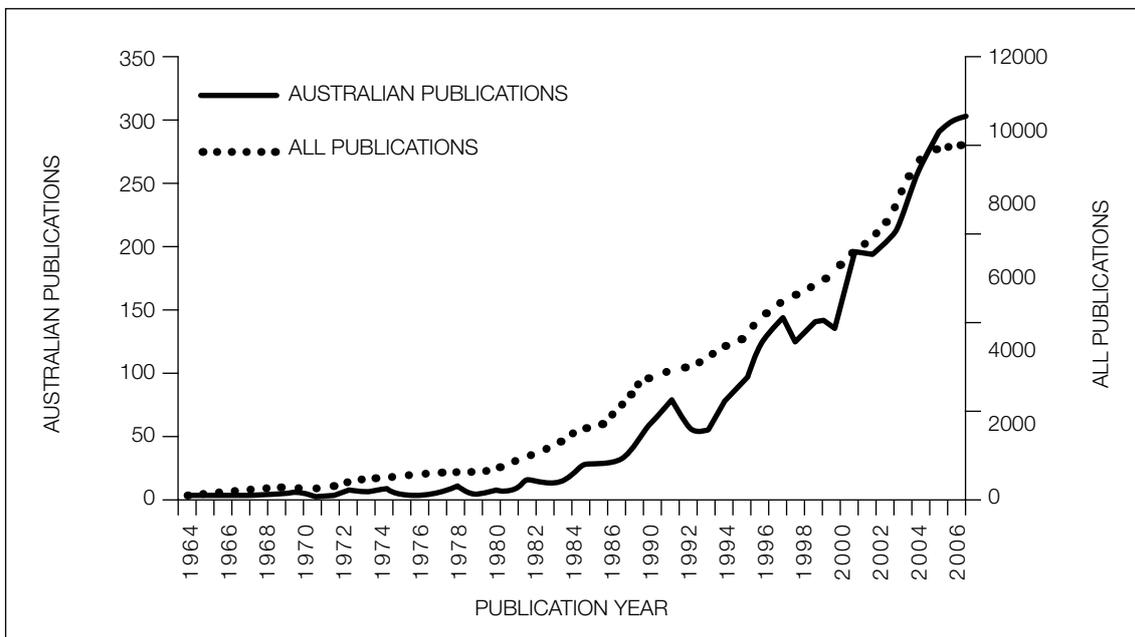
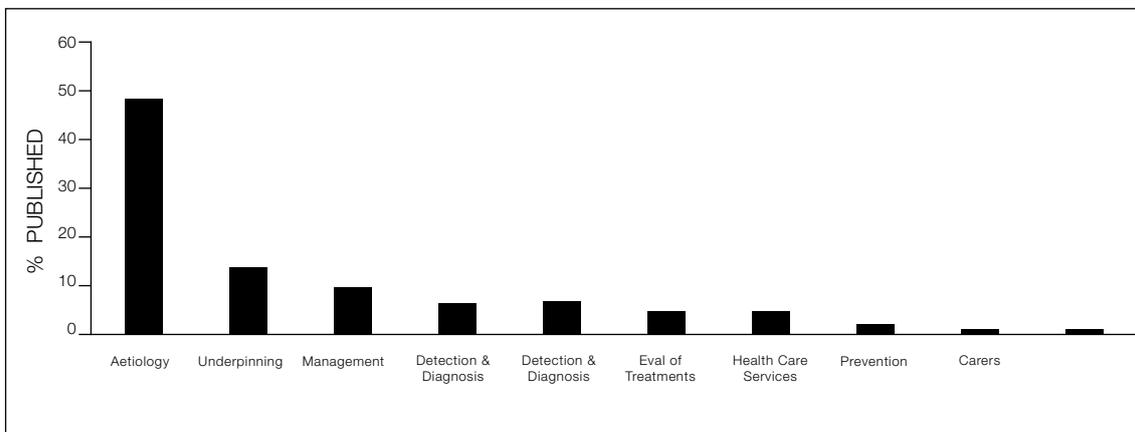


FIGURE 2 Journal publication classifications for dementia research 2005 - 2007

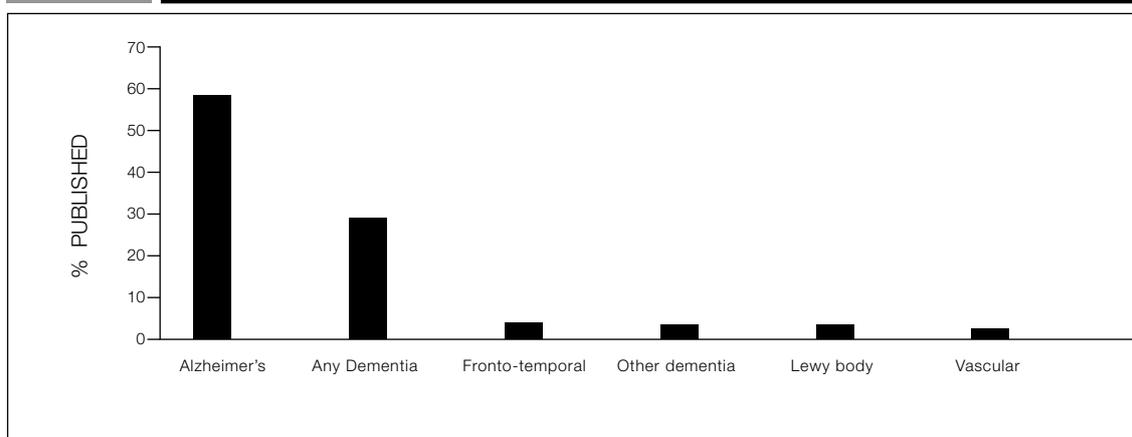


Areas of Australian dementia research 2005-2007

We read the titles and abstracts (and full articles when necessary) of 551 Australian articles on dementia published between 2005 and 2007. The majority focused on dementia aetiology and underpinning research (see Figure 2). Fewer than 10% of articles addressed management, detection and diagnosis, and development of treatments. Fewer than 5% of articles were on evaluation of treatments, healthcare services, prevention, or carers.

Half of the publications concentrated solely on Alzheimer's disease, just over a third on dementia in general, and only small numbers on other types of dementia, such as vascular dementia, Lewy body dementia, and frontotemporal dementia (Figure 3).

FIGURE 3 Type of dementia in journal articles 2005 - 2007



Sixty-three percent of publications reported original results (314 publications), 40% were reviews and 7% were book chapters, case-studies and opinion pieces. Just over 74% (240 studies) of studies reported on original research involving human participants, 63 (19%) were cell studies and 22 (7%) were animal studies. Only a small number of journal publications related to special groups identified by the *Dementia, A National Health Priority Initiative*. Eight (1%) publications addressed younger onset dementia; seven (1%) were on dementia in rural and remote areas; four (<1%) were on persons with dementia from culturally and linguistically diverse (CALD) backgrounds; one publication was on persons with developmental delay and dementia; and one was on Aboriginal and Torres Strait Islander groups.

Groups conducting dementia research

Of 274 Australian organisations that had published dementia journal articles between 2005 and 2007, 108 were university departments, 83 were research institutes, 55 were hospitals and 28 were other health service providers. The majority of organisations were situated in New South Wales (34%) and Victoria (31%), with fewer organisations in Western Australia (12%), Queensland (9%), South Australia (7%), Tasmania (4%) and the Australian Capital Territory (3%). The full list of organisations and the number of publications from each are available in Appendix C (available online at www.alzheimers.org.au).

Clinical trials

The Australian and New Zealand Clinical Trials Register, the US-hosted clinical trials register and the Australasian Consortium of Centres for Clinical Cognitive Research (AC4R) website list 16 clinical trials on dementia currently being conducted in Australia. Eight are drug trials; five are

non-pharmaceutical trials (e.g. physical activity, behavioural support, music and aromatherapy); and three are focusing on the management of dementia. Nine of the trials have a multi-site design, most of which are drug trials and seven trials have only participants diagnosed with Alzheimer's disease. The list of clinical trials is available in Appendix D (available online at www.alzheimers.org.au).

Historic research strengths

A convenience sample of three members of the Alzheimer's Australia's Scientific and Medical Panel and five of their international contacts perceived the historical strengths of Australia's dementia research to be in the areas of the aetiology of Alzheimer's disease, epidemiology, carers and treatment and management. The following researchers are considered to be major contributors to Australian and international dementia research:

Professor Colin Masters has been conducting research on the nature of dementia and other neurodegenerative disorders for more than 30 years. His seminal achievement has been in identifying the molecular and biochemical pathways underlying Alzheimer's dementia, in particular the role of oxidative stress and beta-amyloid in the aetiology of the disease. This work is pivotal to future treatment developments. Professor Masters' current research focuses on elucidating the roles of environmental and genetic factors in Alzheimer's disease.

Professor Tony Jorm has investigated the epidemiology of mental disorders, with particular focus on dementia and depression in the elderly, for more than 20 years. He co-led two major population studies, the Canberra Longitudinal Study for the Elderly and the Personality and Total Health (PATH) Through Life Project. Professor Jorm's key papers on the prevalence, incidence, projections and risk factors for dementia helped to establish dementia as a national priority.

Professor Henry Brodaty has researched clinical aspects of dementia, with a focus on diagnosis and management, for over 20 years. Professor Brodaty pioneered an intensive program for carers, which aimed at relieving stresses associated with caring for persons with dementia. Since this research, carers of persons with dementia have received greater recognition and support. His other projects have included a study of nursing home care for people with dementia, trials of anti-dementia drugs, and the development of a new dementia screening tool for use by general practitioners.

Professor Ashley Bush has researched the aetiology and treatment of Alzheimer's disease. Since 1995, Professor Bush has been investigating the role of major proteins, in particular copper/zinc-binding proteins, in the formation of senile plaques characteristic of Alzheimer's disease. Based on these studies, Professor Bush has developed a new class of anti-Alzheimer's drugs which are currently undergoing clinical trials.

Professor David Ames is known for research on the treatment and management of Alzheimer's disease including pharmacological treatments, and treatments for behavioural disturbance in dementia. He leads the Australian Imaging, Biomarker and Lifestyle (AIBL) Flagship Study of Ageing. Professor Ames has co-edited many books on dementia including *Dementia, Guide to Psychiatry of Old Age and Cerebrovascular Disease*, and *Cognitive Impairment and Dementia* and is currently editor of the journal *International Psychogeriatrics*.

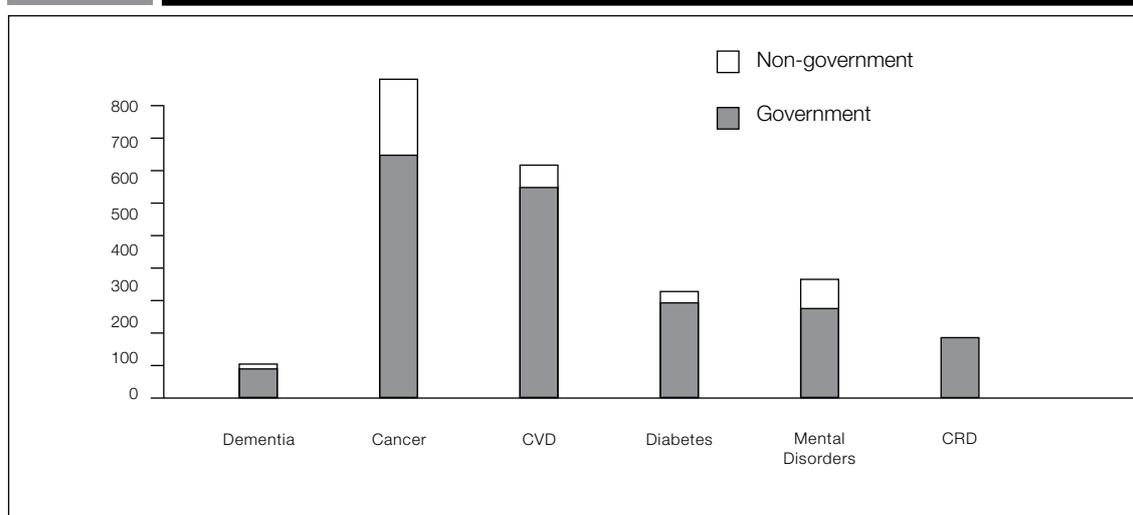
Australian research funding for dementia compared with other chronic conditions

Table 1 shows Australian government and non-government research funding between 2002 and 2007 for dementia and other chronic diseases that account for a significant proportion of disease burden. The New South Wales state government awards block funding to large institutions (\$177.7 million in total 2002-07), therefore funding for specific diseases could not be determined. Thus NSW government funding is not included here. Cancer received the greatest total amount of funding, followed by cardiovascular disease (CVD), diabetes, mental illness and chronic respiratory disease (CRD). Government funding for cardiovascular disease was greatest, while cancer received the most non-government research funding. Dementia received the smallest amount of government and non-government research funding (see Figure 4).

TABLE 1 Total Australian research funding 2002-2007 for selected chronic diseases

Chronic Disease	ARC Funding (\$M)	NHMRC Funding (\$M)	State Govt Funding (\$M)	Total Govt Funding (\$M)	Non-govt Funding (\$M)	Total Funding (\$M)
Dementia	20.0	52.5	0.1	72.7	3.9	76.6
Cancer	65.7	497.9	17.1	580.7	179.1	759.8
Cardiovascular Disease	124.0	369.5	13.5	507.0	47.7	554.7
Diabetes	64.2	164.1	0.4	228.7	25.0	253.7
Mental Illness	23.8	190.8	0.4	214.9	69.2	284.1
Chronic Respiratory Disease	58.9	82.1	0.4	141.5	2.9	144.4

FIGURE 4 Research funding for dementia and other chronic diseases 2002 - 2007



The Australian Institute of Health and Welfare (AIHW) estimated Australian disease burden for 2003 in terms of years of life lost (YLL), years lived with disability (YLD), and total burden measured in disability adjusted life years (DALY). These data are presented in Table 2.

In 2003 cancer accounted for the greatest amount of total disability, as measured in lost DALYs, followed by cardiovascular disease, then mental disorders. Based on this data the AIHW projected the disease burden for 2023 and predicted that the greatest increases in burden will be attributable to dementia and diabetes, whereas the burden attributed to cardiovascular disease will fall. At average annual funding levels between 2002 and 2007 and 2003 DALY estimates, dementia received \$135.24 per lost DALY per year for research funding, the equal second lowest amount per DALY compared to the other chronic diseases (see Figure 5). Research funding relative to 2003 disease burden for dementia is approximately 50% that for cancer. At average annual funding levels (2002-2007) and 2023 DALY projections, dementia only received \$66.14 per future lost DALY, the lowest amount per DALY (see Figure 6).

TABLE 2 Australian research funding and burden of disease for selected chronic diseases in 2003 [7] (Beggs, 2007, personal communication)

Chronic Disease	Average annual funding 2002-2007 (\$M)	2003 [7]			2023 projections	% change 2003-2023
		YLL	YLD	DALY	DALY	
Dementia	12.8	24103	70296	94399	193031	104.5
Cancer	126.6	411953	87463	499416	602384	20.6
Cardiovascular disease	92.4	369365	104429	473794	433277	-8.6
Diabetes	42.3	32295	111536	143831	288341	100.5
Mental disorders	47.3	23154	327391	350545	393017	12.1
Chronic Respiratory Disease	24.1	71339	115383	126157	227632	21.9

FIGURE 5 Research funding per DALY for 2003

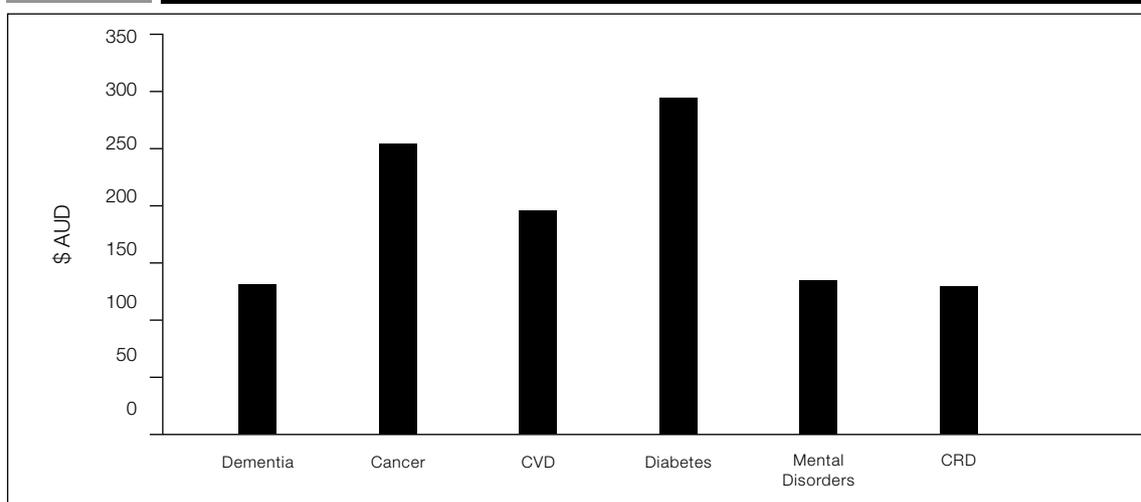
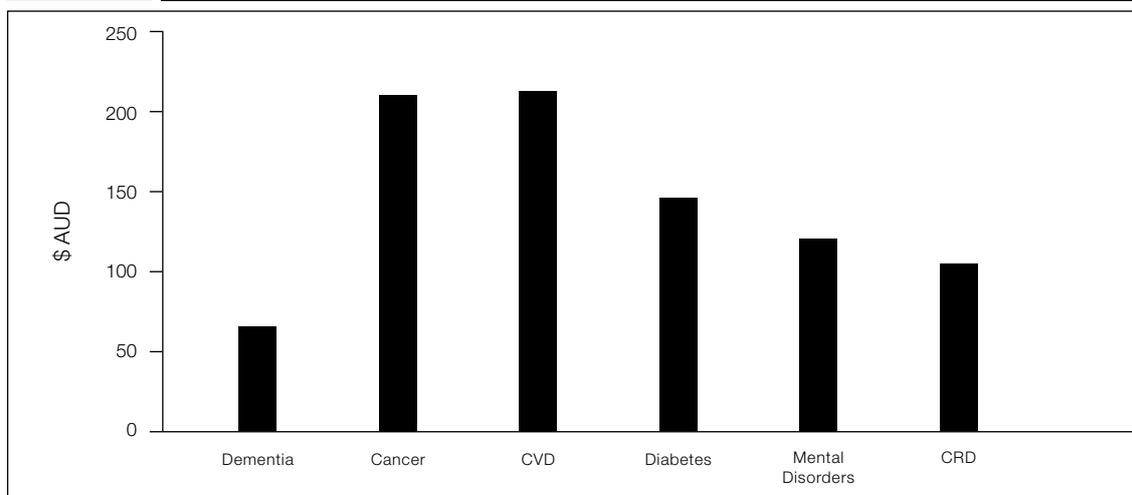


FIGURE 6 Research funding per DALY for 2023

The most recent comparable Australian estimates of annual direct, indirect, and predicted costs of care for selected chronic diseases are shown in Table 3. Direct care costs include the cost of medical care, hospital care and medications. Indirect care costs include loss of productivity from both the person with the illness and his or her carers. These estimates show that mental illness has the greatest total cost of care, followed by cardiovascular disease and diabetes. Projections suggest that by 2023 dementia will have the highest direct care costs. Figures 7 and 8 show that dementia receives the lowest research funding per dollar of 2003 direct care costs (.57 cents) and per dollar of 2023 predicted direct care costs (.16 cents). Research funding per dollar of 2003 direct care costs for dementia is approximately 30% of research funding per dollar of care costs for cardiovascular disease and less than 20% for cancer and diabetes. Research funding per dollar of projected care costs for 2023 for dementia is approximately 5% of research funding per dollar of projected costs for cancer.

TABLE 3 Australian cost of care for selected chronic diseases for 2000-01 and 2023

Chronic Disease	Direct cost of care \$M (AUD) 2000-01 [7]	Indirect Cost of care \$M (AUD) 2000-01	Total Cost of care \$M (AUD) 2000-01	Predicted Direct cost of care \$M (AUD) 2022-23	% increase in cost of care 2000/01 - 2022-23
Dementia	2230	2200	4430	8220	268.6
Cancer	2918	6000	8918	4500	54.2
Cardiovascular disease	5479	5700	11179	6840	24.8
Diabetes	812	9261	10073	4210	418.5
Mental disorders	3741	14964	18705	6690	78.8
Chronic Respiratory Disease	3742	408	4150	730	-80.5

Direct care cost data are from AIHW which are consistently about 1/3rd lower than figures estimated by Access Economics. Indirect cost data for dementia, cancer and cardiovascular disease are from [21], diabetes from [23] for 2005. Published ratios of direct and indirect costs were used to calculate indirect costs for mental illness [24] and chronic respiratory disease [25].

FIGURE 7 Research funding per \$1 of 2000-01 direct cost of care

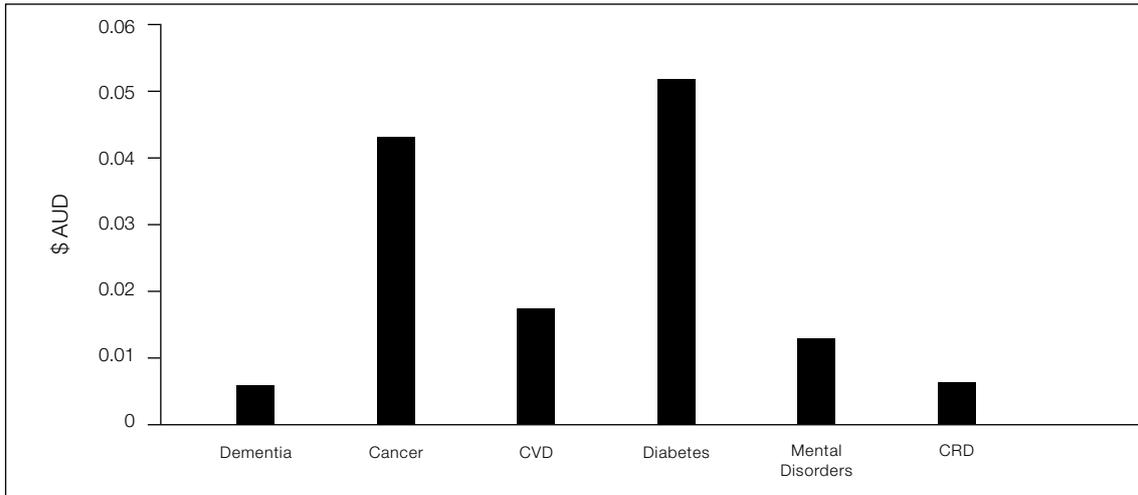
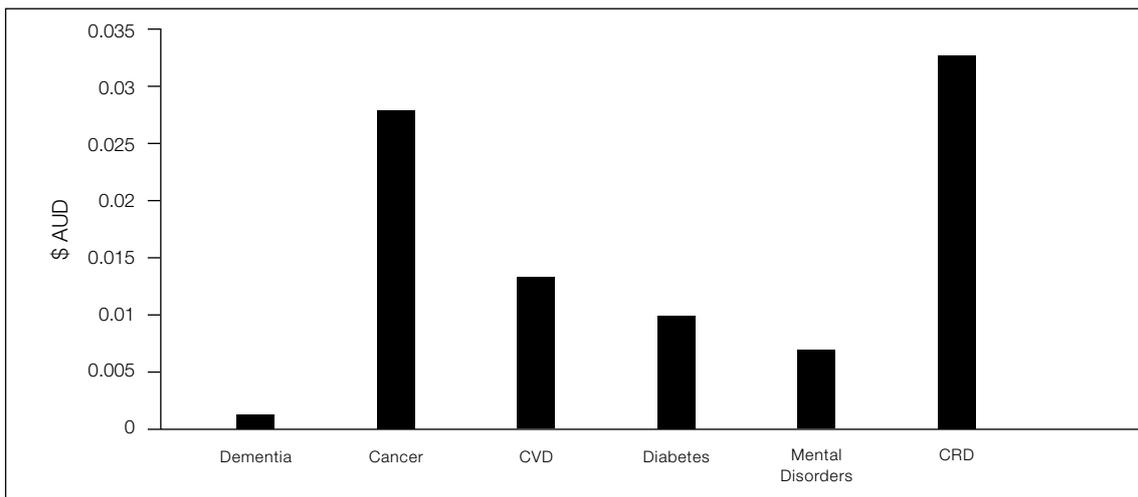


FIGURE 8 Research funding per \$1 of 2023 direct care costs



Australian dementia research funding compared to other select OECD countries.

Table 4 shows that total Australian government and Alzheimer’s organisation funding of dementia research is higher than counterpart organisations in the UK, similar to Canada and much lower than the USA. Australian funding for dementia research is much lower compared to the USA per capita (see figure 9) and in terms of the proportion of gross domestic product (GDP) spent on dementia research (see figure 10).

TABLE 4 Dementia research funding in Australia, USA, UK and Canada in 2007

	Government funding in \$M (AUD)	Alzheimer's Organisation funding in \$M (AUD)	Government funding per capita (AUD)	Total funding per capita (AUD)	Government funding as % of GDP	Total funding as % of GDP
Australia	15.3	0.2	0.73	0.74	0.0015	0.0015
USA	724.7	21.4	2.39	2.46	0.051	0.052
UK	19.2	6.1 +7.9 from Wellcome Trust	0.32	0.55	0.00015	0.00025
Canada	26.0	2.4	0.79	0.86	0.002	0.0022

FIGURE 9 Dementia research funding per capita in 2007

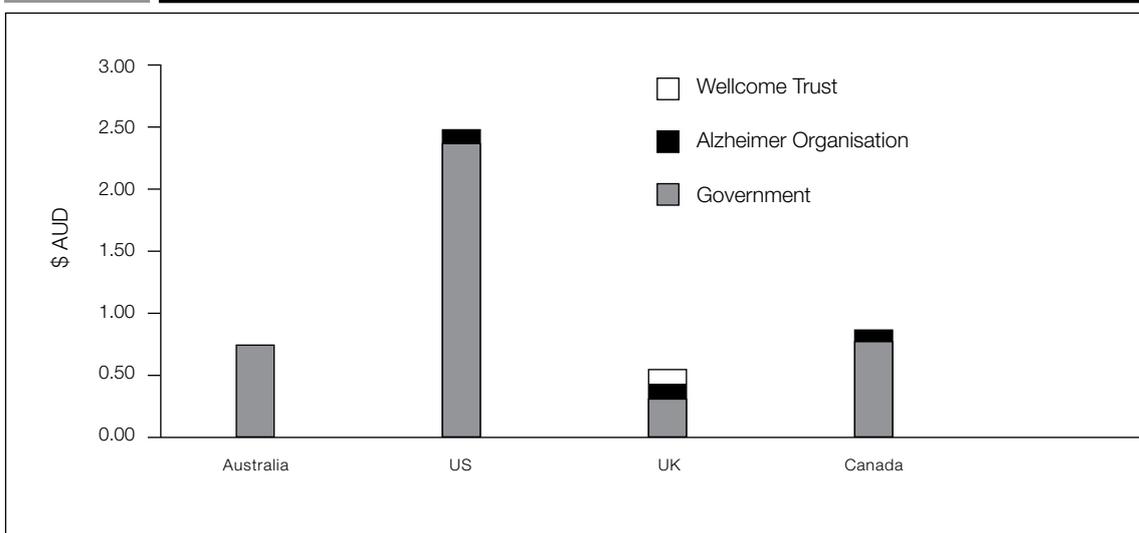
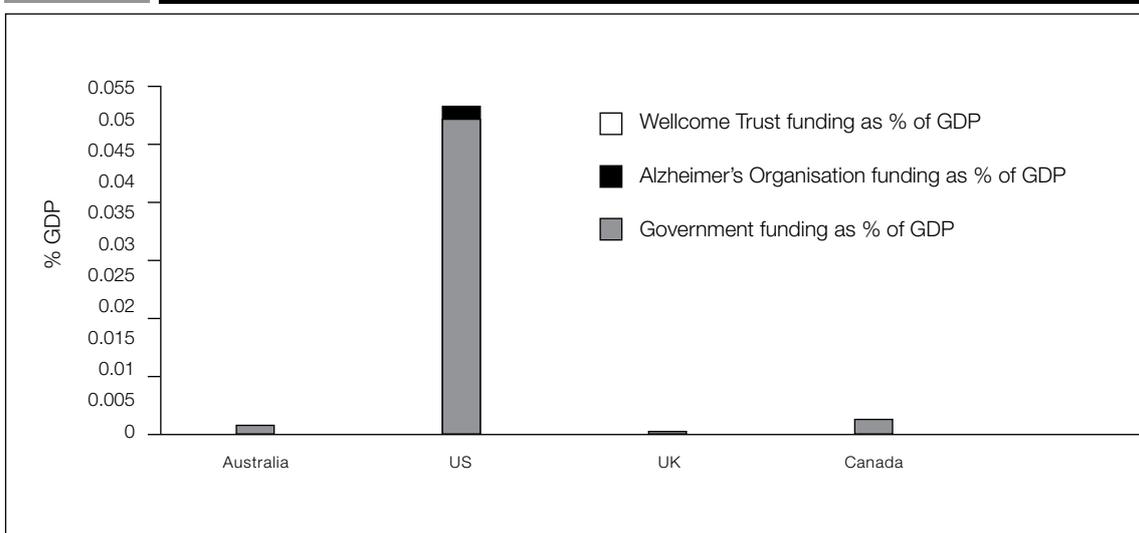


FIGURE 10 Dementia research funding relative to GDP in 2007



DISCUSSION

Australia has, relative to its population (0.3% of the world population), contributed significantly to the global effort in dementia research (2.3% of dementia publications). Australian researchers are world leaders in understanding the aetiology of dementia, its epidemiology, carers, and dementia management.

Are we investing enough in dementia research?

Dementia research is significantly underfunded compared with the USA and relative to other chronic diseases in Australia.

Australian dementia research funding would need to triple to be equivalent, per capita, to the USA. We only collected information on not-for-profit funding from the major Alzheimer's organisations in the other countries and from the Wellcome Trust in the UK. Not-for-profit funding in the US is five times, and in the UK three times, higher per capita than in Australia [20]. Hence the total funding difference between Australia and the USA is likely to be even greater and the relatively low UK funding levels in comparison to the other countries considered here may be an underestimate. The research funding disparity between Australia and the USA is not specific to dementia. It was estimated that in 2000-01 Australia spent 1 to 2 cents per health dollar on research [21]. In comparison, in 2003 the USA spent 5.6 cents per health dollar on research [26].

Total dementia research funding would need to double to be equivalent to the amount per lost DALY spent on cancer research. Dementia research funding would need to increase more than fivefold to be equivalent to the proportion of current direct care costs spent on cancer or diabetes research. Since the estimated dementia care costs used here [7] are conservative compared with other estimates [8] the relative deficit may be larger.

Dementia is the chronic disease that is projected to show the greatest increase in disease burden by 2023. Current research funding does not reflect this projected increase. Funding would need to be increased seven-fold to equate to that received by diabetes, and increased eighteen-fold to equate to that given to cancer and chronic respiratory disease, relative to projected care costs. The proportion of non-government funding for dementia research is low compared to funding for cancer and mental illness. Philanthropic individuals and organisations need to be encouraged to support dementia research.

In 2005 dementia was made a National Health Priority by the Australian Government with \$23 million dollars awarded for research. This has attracted researchers to studying dementia. But the momentum that has been building will dissipate without continued funding.

Are we researching the right areas?

Between 2005 and 2007 more than two thirds of dementia research publications reported on investigations into the causes and development of dementia and on understanding the functions and processes related to normal ageing.

There were limitations to this methodology: books and reports were not included, only book chapters listed on academic databases were included, information on contract research and unpublished research by private industry was not included and only three years of publications were examined. Research relating to health services may be therefore under-represented as it is often published in government or industry reports. Further, the majority of clients of aged care health services have dementia, but this label may not always be used in the title, keywords or abstract.

According to the NHMRC, cost per publication is lowest for biomedical research (\$26,157), higher for clinical medicine (\$32,398) and health services (\$40,474), and greatest for public health and preventative medicine (\$49,477). Taking into account these varying costs by research area and the limitations of our methodology, the data presented in this report suggest that research into the evaluation of treatments, management, health services and prevention has been relatively neglected. This may be because research in these areas usually requires longitudinal methodology with a large number of participants and therefore substantial funding.

Research on the efficacy of pharmacological treatments and on some of the management strategies evaluated in other countries can be adopted relatively easily in Australia. But the Australian health system and Australian people and culture are unique. In order to determine how best to provide care and reduce disease risk, research into health services and prevention needs to be done in situ. The NHMRC has allocated a limited amount of funding specifically for health services research. There are also financial incentives to undertake health services research. Currently only 0.57% of the direct cost of dementia care is spent on research. Residential aged care comprises 85% of the direct cost of dementia, so services that delay institutionalisation could have considerable cost savings. It has been estimated that if the average onset of dementia had been delayed by five years from 2005 it would have resulted in a 50% reduction in new cases each year, and 35.2% fewer cases by 2020 and 48.5% fewer cases by 2040— a saving of \$13.5 billion and by 2040 \$67.5 billion [27].

Even the best research has little impact unless findings are known and incorporated into everyday practice. Much research is published in academic journals but does not reach practitioners or the public. Currently it takes an average of 17 years for research findings to be implemented in clinical practice [28]. Knowledge transfer is a long-term iterative process and requires specialist communicators, time, and money [29-31]. Researchers are usually not funded to translate and promulgate their results beyond publication and conference presentations. The NHMRC has recognised the need to improve access to good research evidence [32]. To get the most out of dementia research, funding needs to be allocated for the dissemination of results.

What needs to happen

- Annual Australian expenditure on dementia research should be increased three-fold from \$12.8 million (0.57% of the total direct cost of dementia) to \$36 million (1.6% of the total direct cost)
- Dementia should be made a National Health Priority Area by the National Health and Medical Research Council.
- Funding should be allocated specifically for dementia service delivery and prevention research.
- Funding should be allocated to disseminate dementia research findings.

CONCLUSIONS

The dementia epidemic is upon us. We need to prepare for the deluge through policy and service development, informed by research. Research funding for dementia must be at least trebled so that we can continue investigating areas of strength and address research gaps in service delivery and prevention. We must also ensure that results are translated into practice.

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DECLARATION OF INTERESTS

Dr Low is an NHMRC research fellow, Ms Gomes is a research assistant, and Professor Brodaty is Director at the Dementia Collaborative Research Centre: Assessment and Better Care Outcomes.

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