

McKeon Review Secretariat
PO Box 4226
MANUKA ACT 2603

Dear Mr McKeon,

**Submission to the Strategic Review of Health and Medical Research from the
Consumer Dementia Research Network**

Alzheimer's Australia welcomes the opportunity to contribute to this important and timely review of health and medical research in Australia.

Dementia is the chronic disease of the 21st century, yet dementia research remains underfunded in comparison to other chronic diseases in Australia with dementia receiving only one sixth of the funding which is provided for cancer research. Other countries such as France, the US and most recently the UK have recognised that dementia is underfunded and have announced initiatives to increase investment in dementia research. Australia must not be left behind.

This review provides a critical opportunity to re-examine the processes through which funding is allocated to different health priority areas. It will enable the Panel to consider different approaches for rebalancing current funding to achieve better health outcomes for Australians in priority areas such as dementia.

To assist the Panel in its consideration of these issues, Alzheimer's Australia commissioned new analysis of 10 years of NHMRC research funding data for dementia and other chronic diseases. We are most grateful to Professor Kaarin Anstey from the ANU for undertaking this work, and Professor Warwick Anderson, CEO of the NHMRC for providing the data and supporting this undertaking.

Alzheimer's Australia is a consumer organisation providing support and advocacy for the 280,000 people living with dementia, and the 1.2 million people who provide them with support and care. As a consumer organisation, we give equal priority to improving services and investing in research. Our own Alzheimer's Australia Dementia Research Foundation currently allocates more than \$1 million per annum

through competitive peer-reviewed processes to support new and emerging dementia researchers to establish their careers.

Alzheimer's Australia has also taken a lead in empowering consumers to play an active role in all stages of dementia research, and to determine priorities and direct efforts to improve dementia services through knowledge translation. Along with a need for priority-driven funding for dementia research, these two issues: consumer involvement in research, and knowledge translation, form the key themes of this submission.

This submission has been developed under the guidance of consumers – people with dementia and their carers – and is submitted by the 25 members of the Consumer Dementia Research Network. Alzheimer's Australia greatly values and appreciates the input of Network members Tara Quirke, Kathy Williams, Leo White, Judy Wheaton, Elaine Todd and Anne Turner for the time and energy they have put into this task over the past two months, and Dr Chris Hatherly, Alzheimer's Australia National Research Manager for assisting in the preparation of the submission. I would also like to acknowledge the contribution of members of the Alzheimer's Australia Scientific and Medical Panel, and Dr Jan Davies for her valuable support and feedback.

I recommend this submission to the Panel, and encourage you to talk further with Alzheimer's Australia and members of the Consumer Dementia Research Network during your forthcoming public consultations and thereafter.

Sincere regards,

A handwritten signature in blue ink, appearing to read 'Ita Buttrose', with a horizontal line underneath.

Ita Buttrose AO, OBE
President, Alzheimer's Australia

30 March, 2012

McKeon Review Secretariat
PO Box 4226
MANUKA ACT 2603

Dear Mr McKeon,

**Submission to the Strategic Review of Health and Medical Research from the
Consumer Dementia Research Network**

The Alzheimer's Australia Consumer Dementia Research Network is pleased to have the opportunity to contribute to this critical and timely review of Australia's health and medical research system.

The Consumer Dementia Research Network, or CDRN, comprises 25 people of various ages, from all walks of life and every state and territory of Australia. We share a profound, intimate, and for most of us, a devastating experience of the insidious and irreversible neurodegenerative condition called dementia

Five of our 25 members are people with dementia. These five brave and inspirational individuals have grasped the enormity of their diagnosis and, while dealing with the utter chaos that dementia makes of people's lives, have found the energy and the drive to contribute to the global research effort to do something about this terminal disease. They are not doing so necessarily for themselves, but in the hope of better outcomes for generations of people who will inevitably be dealing with dementia in the future.

The rest of our group are people who care for a spouse or parent with dementia, or who have cared for, and lost, a loved one – sometimes more than one – to this fatal condition in the recent past.

We are people who leave behind lives, jobs and friends for many years to support, as best we can, our loved ones as they experience the fear, confusion, grief and frustration of slowly losing their memories, their abilities, their understanding and eventually, the essence of themselves. For carers, the years of progressively increasing physical and mental exhaustion, grief, guilt and frustration may at times

be partly offset by moments of love, humour and joy, but they go largely unnoticed and unrecognised by society.

We believe that dementia will eventually be beaten through research, and the opportunity for us to contribute in a range of ways to the dementia research effort is one of the primary reasons that our 25 members of the CDRN commit time and seemingly endless energy to the Network and the very important work that it is doing.

However, we know that health and medical research does nothing to benefit consumers unless it is acted upon through regulation, government programs, or directly by those working in the healthcare system. This action rarely happens by itself; instead requiring skilled and well-resourced facilitation; a circular translation of knowledge from one group of health system stakeholders to the other.

Promoting such facilitation in the field of dementia is the other reason that our members are passionate about the work we are doing. We have identified areas of dementia care where there are existing and well-established research findings that we believe could improve the quality of life for people with dementia. Through Alzheimer's Australia, and generous support from the J.O. and J.R. Wicking Trust, Bupa Care Services, and the Dementia Collaborative Research Centres, we have taken the opportunity to direct and fund knowledge translation projects that take those research findings and apply them as widely as possible to critical failings of the health and aged care systems that each of us, as consumers, have experienced first hand.

This submission represents our collective views of three crucial elements that need to be built into Australia's health and medical research system to achieve better outcomes for millions of people like ourselves.

These are:

1. Recognition of dementia as a national health priority area, increasing dementia research funding, and increasing the capacity of the dementia research sector to undertake rigorous, and high quality research;
2. A carefully planned, co-ordinated, and well-funded approach to rapidly translating new and existing findings directly into better quality healthcare; and

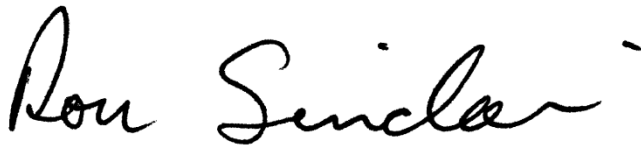
3. A greater emphasis on involving and engaging consumers – people with direct experience of health conditions and systems of care – into the research enterprise.

Each of these issues is covered in greater detail in the following submission, which we recommend unreservedly to the Panel.

We will look forward to hearing from the Panel, and would welcome the opportunity to meet with Panel members both at the planned public consultations, and separately as a group.

We thank you for your time.

Regards

A handwritten signature in black ink that reads "Ron Sinclair". The signature is written in a cursive, flowing style.

Ron Sinclair,
Chair, Consumer Dementia Research network

30 March, 2012

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**Submission to the McKeon Review of Health and
Medical Research in Australia**

from

The Consumer Dementia Research Network

supported by

Alzheimer's Australia

Table of Contents

1. Summary and Recommendations.....	3
1.1. Recognising dementia as a national health priority area, and prioritising dementia research capacity building	3
1.2. Translating existing evidence into better health and aged care practice	4
1.3. Consumer engagement in health and medical research	5
2. Introduction	6
3. Recognising dementia as a national health priority area, and prioritising dementia research capacity building.....	7
3.1. Recognising dementia as a national health priority area	7
3.2. Rebalancing the health and medical research system to increase opportunities for priority-driven research	8
3.3. Dementia research funding in comparison to other chronic diseases.....	9
3.4. NHMRC funding for dementia in comparison to other chronic diseases.....	10
4. Translating existing evidence into better health and aged care practice.....	19
5. Consumer engagement in health and medical research.....	21
6. Conclusion	24
Appendix A. Evaluation of NHMRC Data on the Funding of Dementia Research in Australia	25
Appendix B. Alzheimer’s Australia Consumer Dementia Research Network (CDRN)	48
Appendix C. Report of the Interim Evaluation of the Consumer Dementia Research Network.....	50
Appendix D. Outcomes of the joint NHMRC-Alzheimer’s Australia Workshop: Translating Dementia Care Research into Better Practice.....	136

1. Summary and Recommendations

This submission sets out a number of issues and makes recommendations to assist the Review Panel with its objective of developing a 10-year strategic plan for health and medical research in Australia. The submission focuses primarily on publicly funded research.

These issues and recommendations are grouped into three key areas:

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1. Recognising dementia as a national health priority area, and prioritising dementia research capacity building;
2. Translating existing evidence into better health and aged care practice;
3. Consumer engagement in health and medical research.

1.1. Recognising dementia as a national health priority area, and prioritising dementia research capacity building

Key Issues

Dementia is the chronic condition of the 21st Century. As the number of people with dementia grows from 280,000 to one million over the coming decades, dementia will make increasing demands on the health and aged care systems. As a condition that is presently incurable, research is the first line of defence against the looming dementia epidemic. Yet the gap between public funding for dementia research and research on other chronic diseases is growing. New analyses of NHMRC funding data commissioned to inform this submission show that the critical issue is insufficient capacity within the dementia research sector to compete for vital research funding, and a lack of capacity-building to address this issue. Disciplinary research is highly specialised, and research training is slow. Unless there is strategic and systemic focus on building dementia research capacity in terms of people and infrastructure, the dementia research sector will continue to fall behind other chronic disease areas, will be increasingly dependent on the research outcomes generated outside Australia, and will be unable to deliver timely, contextualised and targeted research evidence and evidence-based innovation that responds to critical health and aged care system needs.

Recommendations

1. That dementia should be recognised as a national health priority area, and made a focus of priority-driven health and medical research;
2. That Australia's publicly funded health and medical research system should be rebalanced over time to provide an increased emphasis on priority-driven research funding in areas such as dementia;
3. That immediate additional funding of approximately \$40 million per annum is allocated to dementia research through the NHMRC to close the funding gap between dementia and other chronic conditions. This would result in a funding level

of approximately \$60 million per annum, or approximately 1% of the direct costs of dementia related health and aged care.

4. That effort is made to increase research capacity in current and emerging health priorities areas such as dementia by allocating significant additional funding to boost the number of postgraduate scholarships, early career fellowships and capacity development fellowships awarded in these areas.

These recommendations relate to MFR 12, under Review Question Three: *What are the health and medical research strategic directions and priorities and how might we meet them?* And MFR 6 under Review Question One: *Why is it in Australia's interest to have a viable, internationally competitive health and medical research sector?*

1.2. Translating existing evidence into better health and aged care practice

Key Issues

There are significant gaps between existing evidence and mainstream practice in many areas of medicine, health and aged care. These gaps result in substantial inefficiencies in the expenditure of public funding, and failures in the health and medical care of consumers. Addressing these gaps and improving practice on a large-scale is complex, expensive, and time-consuming, however there are a range of strategies falling under the banner of knowledge translation that can be successfully deployed. These strategies cover a spectrum of activity from translational research through to large-scale public awareness campaigns, and require involvement and collaboration between a range of stakeholders, including researchers, health and medical service providers, policy makers, regulators, and consumers..

Recommendations

5. That the review panel consider the experience and the learning of organisations such as Alzheimer's Australia that have been engaged in efforts to translate existing evidence into better practice in specific areas such as dementia care
6. That the Government devote significant resources to developing new initiatives and supporting existing initiatives (such as the NHMRC Partnership Centres, and the Alzheimer's Australia National Quality Dementia Care Initiative), that are aimed at bringing together key stakeholders, including consumers, with the objective of translating existing evidence into wide-spread improvements in practice.

These recommendations relate to MFR 4, 8 and 9, under Review Question Four: *How can we optimise translation of health and medical research into better health and wellbeing?*

1.3. Consumer engagement in health and medical research

Key Issues

Most publicly funded health and medical research is managed and funded in a way that promotes investigator-driven research. Investigator-driven research is appropriate for most basic biomedical research, however in more applied areas of clinical, public health and health services research, consumers (recipients of health and aged care services) as well as health policy makers and services providers have limited opportunities for input into the conduct of research and the development of research agendas. This is despite their close association with the system and their detailed knowledge in many cases of health system failings, barriers and facilitators to change. As a consequence of limited consumer involvement and engagement:

- research is often not well targeted to priority issues within the health system;
- the outcomes are often not communicated in a way that is accessible or relevant to consumers; and
- the research consequently fails to be effectively and efficiently translated into better healthcare policy and practice.

Recommendations

7. That formal independent mechanisms be established for engaging consumers in all aspects of health and medical research in specific disease areas. The Consumer Dementia Research Network (CDRN) is recommended as a successful model of such a framework that could easily be implemented in other fields, with Government or other funding, and through the support of relevant consumer organisations.
8. That the NHMRC ensure ongoing funding for the CDRN through the Dementia Collaborative Research Centres or another mechanism, as recommended by the Centre for Health Service Development in their interim report on the CDRN.

These recommendations relate to MFR 7, under Review Question Two: *How might health and medical research be best managed and funded in Australia?*

2. Introduction

Dementia is a clinical syndrome characterised by cognitive impairment, behavioural disturbance and loss of functional abilities. It can be caused by over 100 neurological conditions, including Alzheimer's disease which accounts for 50-70% of all dementia cases. Other common causes of dementia include vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Most causes of dementia are neurodegenerative, and at present there are no curative treatments or clinical interventions that can delay or reverse these diseases. As a result, dementia is considered to be a terminal condition.

Dementia currently affects almost 280,000 Australians.¹ It places significant demands on the health and aged care systems, and on the estimated 1.2 million family members and friends who provide countless hours of unpaid support and care².

While dementia can occur in individuals as young as 30, it is more common as people age. Consequently, as the population ages and known risk factors including hypertension and diabetes increase³, so too will the prevalence of dementia. Modelling from Deloitte Access Economics shows that there will be over 500,000 people with dementia by 2030, and close to 1 million by mid-century.⁴

The direct cost of dementia to the health and aged care systems is approximately \$6 billion per annum.⁵ Added to this is the financial burden on family carers who often provide 24 hour care. The replacement cost of family carers alone is estimated to be \$5.5 billion per annum.⁶ By 2060, the health and aged care costs of dementia are projected to rise to \$83 billion (in 2006-07 dollars), and will exceed those of any other health condition⁷.

With prevalence increasing and a projected shortage of more than 150,000 paid and unpaid carers by 2029⁸, dementia is the major chronic condition of the 21st Century.

This submission has been prepared by members of the Alzheimer's Australia Consumer Dementia Research Network (CDRN). The CDRN is a group of 25 people with dementia and family carers from across Australia who share a commitment to improving the quality of dementia care in Australia through research and research translation.

¹ Deloitte Access Economics (2011). *Dementia Across Australia: 2011-2050*. Report for Alzheimer's Australia. Available: www.fightdementia.org.au/research-publications/access-economics-reports.aspx

² Pfizer Health Report (2011; issue #45) *Dementia is everybody's business*. Available: www.fightdementia.org.au/research-publications/pfizer-health-reports.aspx.

³ Biessels, G. J., Staekenborg, S., Brunner, E., Brayne, C., & Scheltens, P. (2006). Risk of dementia in diabetes mellitus; A systematic review. *Lancet Neurology*, 5, (1), 64-74

⁴ Deloitte Access Economics (2011). *Caring Places: Planning for Aged Care and Dementia 2010-2050*. Available www.fightdementia.org.au/research-publications/access-economics-reports.aspx

⁵ Access Economics (2003). *The dementia epidemic: Economic impact & positive solutions for Australia*. Available www.fightdementia.org.au/research-publications/access-economics-reports.aspx

⁶ Access Economics (2010). *Caring Places: Planning for Aged Care and Dementia 2010-2050*. Available www.fightdementia.org.au/research-publications/access-economics-reports.aspx

⁷ Access Economics (2003). *Op cit*

⁸ Access Economics (2009). *Making Choices, Future Dementia Care: Projections, Problems and Preferences*. Available www.fightdementia.org.au/research-publications/access-economics-reports.aspx

There are significant structural and process issues within the health and medical research sector that impact on the quality, reach and translation of research in dementia, as in other fields. The CDRN and Alzheimer's Australia expect that these will be key issues for the review, and that others will elaborate the case for change. As a funder of research, Alzheimer's Australia is a member of Research Australia, and supports the submission and recommendations made by that organisation.

The key issues dealt with in this submission are those considered by members of the CDRN to be of utmost importance to ensuring that the health and medical research sector is able to address the looming dementia epidemic in the future. These issues are:

1. Prioritising dementia research funding, and ensuring that the dementia research field has the capacity to undertake vital research;
2. Improving the translation of existing research into better practice; and
3. Doing more to engage consumers in the research process.

3. Recognising dementia as a national health priority area, and prioritising dementia research capacity building

3.1. Recognising dementia as a national health priority area

Dementia is the third leading cause of death in Australia⁹, and a leading cause of disease and disability burden. While the burden associated with other conditions such as heart disease is gradually decreasing, dementia-related burden of disease is growing at a faster rate than any other condition,¹⁰ and is projected to become the leading cause of disability burden in Australia by 2016.¹¹

The Federal Government currently recognises eight National Health Priority Areas (NHPAs). These are cancer, diabetes, cardiovascular disease, mental health, asthma, arthritis and related musculoskeletal conditions, injury prevention and obesity.

Formal recognition as a NHPA provides a vehicle for priority collaborative action to improve health outcomes for all Australians, including through increased research funding. Dementia is not currently included as a national health priority area, despite the comparable economic and societal impacts of the condition, and the projected growth in these impacts as the prevalence of dementia continues to grow.¹²

By failing to recognise dementia as a national health priority area, Australia is losing opportunities to optimise the research and policy response to dementia, including vital efforts

⁹ ABS (2012). *Causes of death in Australia: 2010*. Cat No: 3303.0. Available: www.abs.gov.au/ausstats/abs@.nsf/mf/3303.0/

¹⁰ Low, L-F., Gomes, L., & Brodaty, H. (2008). Australian Dementia Research: Current status, future directions? *Alzheimer's Australia Paper 16*. Available: www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx

¹¹ Access Economics (2003). *Op cit*

¹² Access Economics (2003). *Op cit*

to prepare for and ameliorate the impact of dementia in the future. France, the USA, and the UK have all made very significant additional funding commitments to dementia and dementia research in the past 12 months¹³. Australia must not fall behind.

Given the importance of national health priority area status to health and medical research funding, it is vital that dementia be included as a national health priority area.

Recommendation 1. *That dementia should be recognised as a national health priority area, and made a focus of priority-driven health and medical research.*

3.2. Rebalancing the health and medical research system to increase opportunities for priority-driven research

The majority of public funding for health and medical research in Australia is allocated to investigator-driven research through competitive, peer-reviewed grant processes. This system has served Australia well for many decades, and has fostered significant international leadership by Australian researchers in many fields.

However, the competitive investigator-driven nature of health and medical research funding can arguably be seen to favour disease areas that have significant and established infrastructure, networks and development pathways to attract new researchers and to obtain competitive research funding. These are areas such as cancer and cardiovascular disease where Australian researchers have been pioneering new knowledge and making important advances at the cutting edge of medical science for decades.

The research undertaken in these areas cannot be undervalued, not least because there are important links between dementia and conditions such as cardiovascular disease, diabetes, obesity and HIV Aids. However, the capacity of established research fields to attract funding and deliver training can result in them being seen as more promising career options than emerging areas where research funding, especially for new researchers, can be difficult to come by. Without talented new researchers, emerging health priority areas such as dementia can struggle to gain a research foothold.

There are clear and compelling arguments for rebalancing the current system of publicly funded health and medical research from a predominantly investigator-driven model to one that has an equal emphasis on priority-driven research in health areas that present the greatest health system needs now and in the future. The CDRN and Alzheimer's Australia expect that this will be a key issue for the review, and that others will elaborate the case for change. Such a change is essential to allow relatively, but vitally important research areas such as dementia to increase capacity and deliver high quality evidence that responds directly to health priorities now and in the future.

¹³ Reports available: www.hhs.gov/news/press/2012pres/02/20120207a.html; <http://alzheimersweekly.com/content/french-president-takes-global-dementia-challenge>; www.guardian.co.uk/society/2012/mar/26/dementia-research-funding-to-double

Recommendation 2. *That Australia's publicly funded health and medical research system should be rebalanced over time to provide an increased emphasis on priority-driven research funding in areas such as dementia.*

3.3. Dementia research funding in comparison to other chronic diseases

Research is our first line of defence against the looming dementia epidemic, yet in terms of prevalence, disability burden and economic impact, dementia research remains dramatically underfunded compared to other chronic conditions. In 2011-12, the National Health and Medical Research Council's forecast expenditure on research into Alzheimer's disease and other forms of dementia was \$24.0 million. Over the same period, the forecast investment is:

- \$159.2 million on cancer research;
- \$92.4 million on cardiovascular disease;
- \$71.2 million on research into diabetes;
- \$53.6 million on mental health research; and
- \$14.2 million on asthma research.¹⁴

Economic modelling commissioned by Alzheimer's Australia in 2008 examined research expenditure as a proportion of disability burden and direct care costs across several chronic diseases.¹⁵ This report found that the ratio of research funding to direct care costs was twice as big for cardiovascular disease as for dementia, and almost ten times as big for both diabetes and cancer. Relative to disability adjusted life years, the ratio of dementia research expenditure was equivalent to mental health, and around half that of diabetes and cancer. This report recommended a three-fold increase in dementia research funding through the NHMRC to bring dementia research expenditure into line with cardiovascular disease and cancer research.

Recommendation 3. *That immediate additional funding of approximately \$40 million per annum is allocated to dementia research through the NHMRC to close the funding gap between dementia and other chronic conditions. This would result in a funding level of approximately \$60 million per annum, or approximately 1% of the direct costs of dementia-related health and aged care.*

To further investigate the nature of dementia research funding in Australia and identify gaps, Alzheimer's Australia commissioned the Centre for Research in Ageing, Health and Wellbeing at the Australian National University to undertake a detailed analysis of funding data from the NHMRC. The NHMRC assisted this effort by providing new data on the funding and fundability status of dementia research applications that has not previously been publicly available. The analyses undertaken compared dementia research funding over time with funding for disease areas of:

- Cancer
- Cardiovascular disease

¹⁴ www.nhmrc.gov.au/grants/research-funding-statistics-and-data/burden-disease. Retrieved 7 March, 2012

¹⁵ Low, *op cit*.

- Diabetes
- Mental Health
- Asthma

A summary of the outcomes of these analysis are provided here, and the full report, including methodology and the results of a sensitivity analysis on NHMRC research funding keywords is included at Appendix A.

3.4. NHMRC funding for dementia in comparison to other chronic diseases

Dementia research in Australia is significantly underfunded by the public system compared to other chronic diseases that place equal or lower demands on the health system. Analyses of the publicly available NHMRC data indicate that this is a trend that has been continuing for at least the past decade. As can be seen in Figures 1 and 2, both overall funding commitment and overall expenditure from 2002-2011 were low for dementia relative to other chronic disease areas apart from asthma. Importantly, funding for dementia showed very little increase over the time period. This has meant that since 2002, the difference in funding levels for dementia versus diabetes, cancer, cardiovascular disease (CVD) and mental health has grown significantly.

Figure 1. Funding Commitment by Chronic Disease

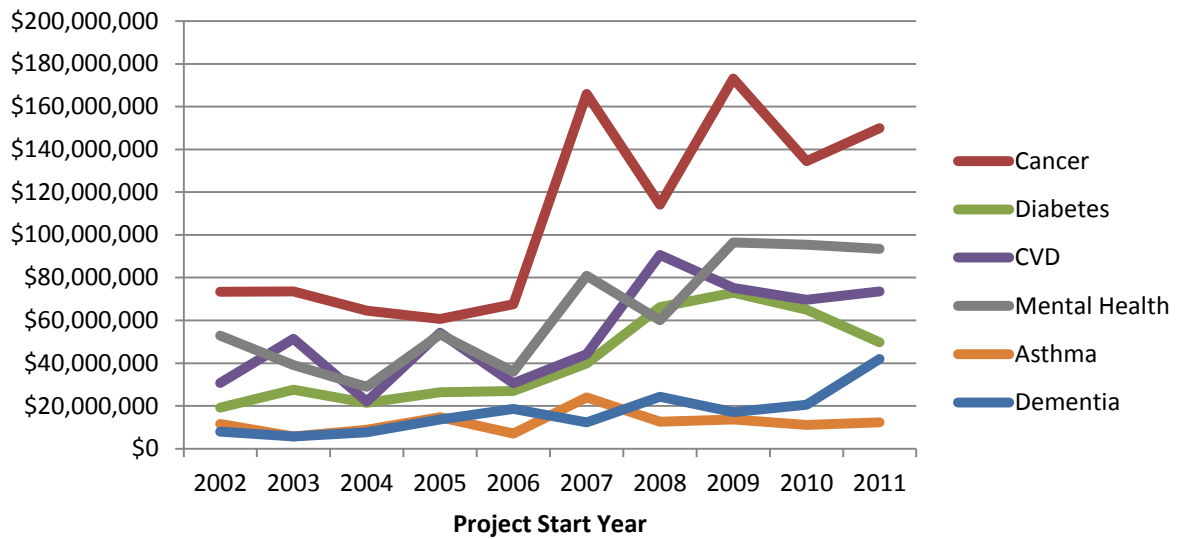
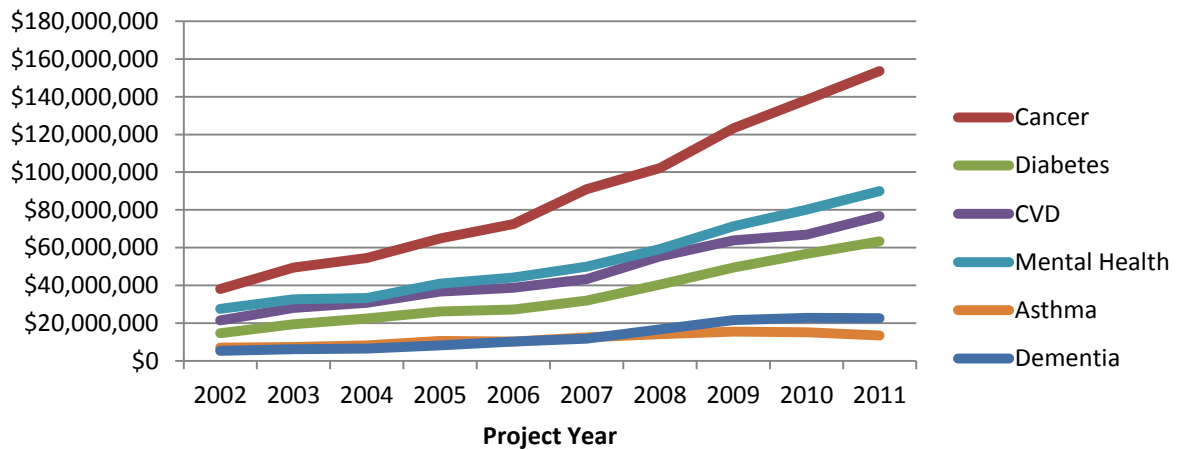


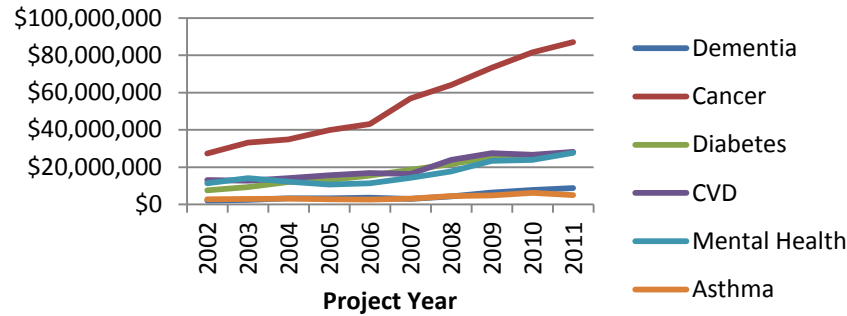
Figure 2. Funding Expenditure by Chronic Disease



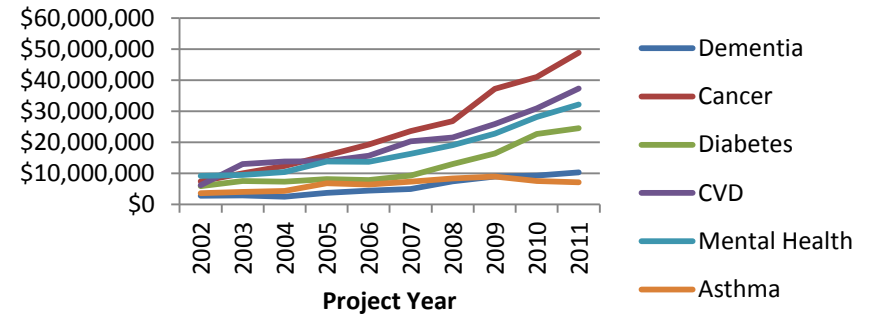
Relatively lower rates of funding for dementia are not restricted to any specific research area, with similar funding trends evident across broad research areas (Figure 3), and research funding groups (infrastructure, people or research support; Figure 4).

Figure 3. Funding expenditure by Chronic Disease and Broad Research Area, 2002-11

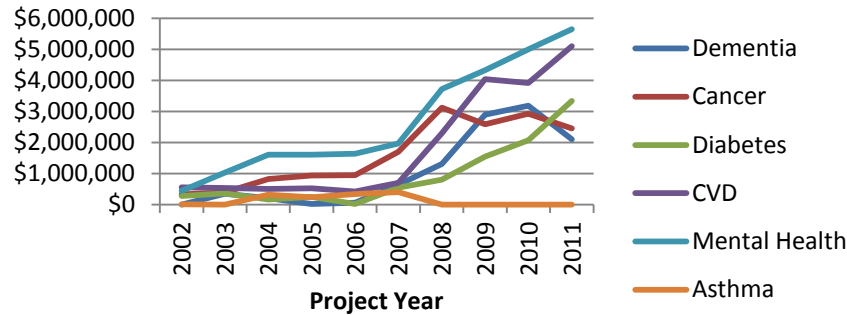
Basic Science Funding Expenditure by Chronic Disease



Clinical Medicine Funding Expenditure by Chronic Disease



Health Services Funding Expenditure by Chronic Disease



Public Health Funding Expenditure by Chronic Disease

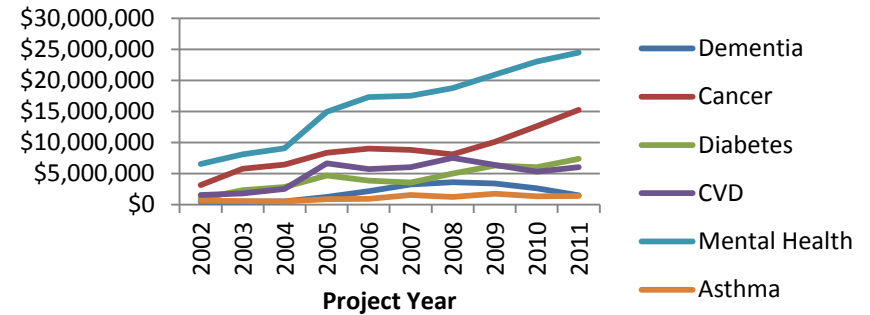
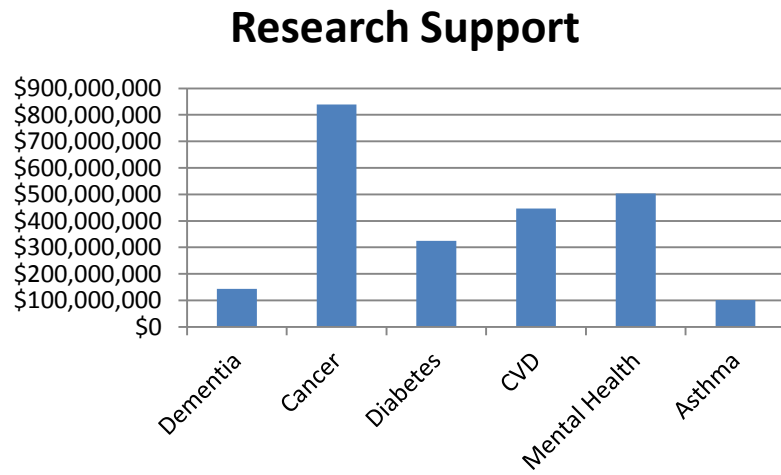
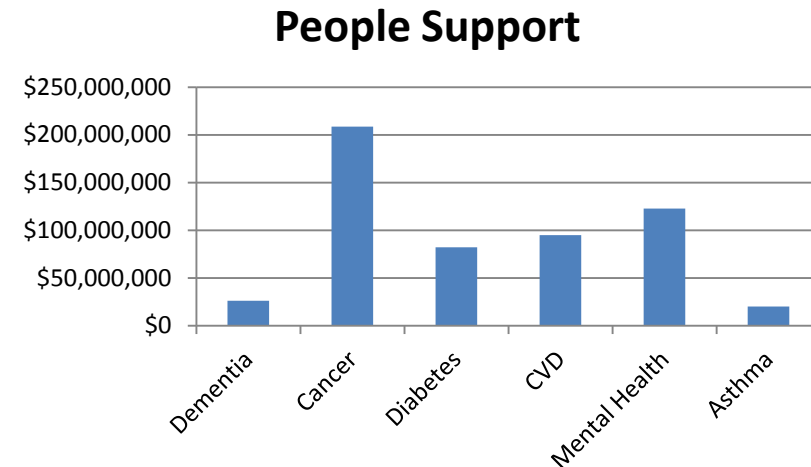
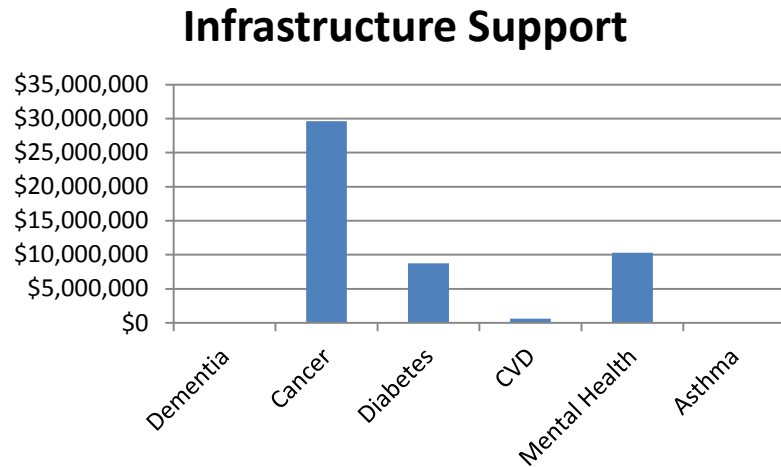


Figure 4. Cumulative funding expenditure by Chronic Disease and Research Group 2002-2011



Health and medical research funding is primarily allocated on a competitive basis to investigator driven research. This means that the low levels of dementia research funding relative to other chronic conditions could be due to:

- A relatively low success rate of dementia research funding applications
- A relatively low value of successful dementia research funding applications
- A relatively low number of dementia research funding applications

Success rates of dementia research funding applications

Confidential data supplied to Alzheimer’s Australia by the NHMRC indicates that success rates for dementia research applications have remained equivalent to success rates for applications across all disease areas since 2005 (Figures 5 and 6; data for success rates in other disease areas was not released by the NHMRC and is not publicly available).

Figure 5. Success Rates by Year of Application

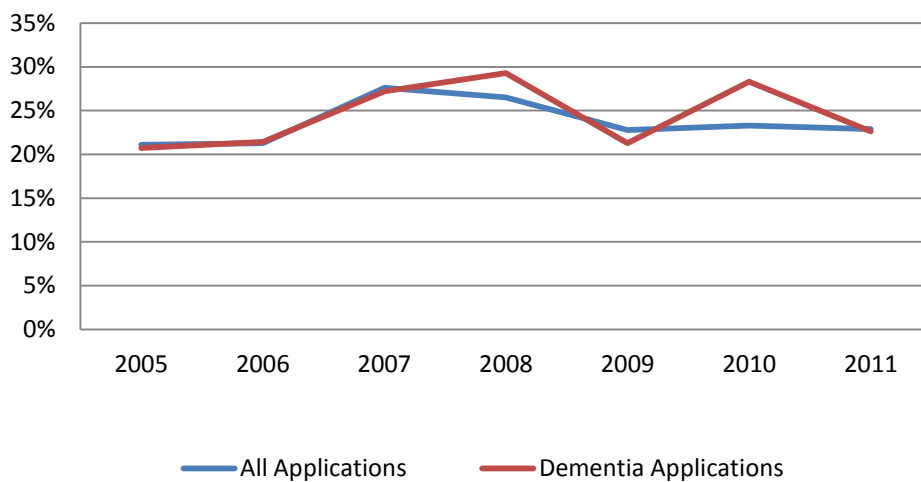
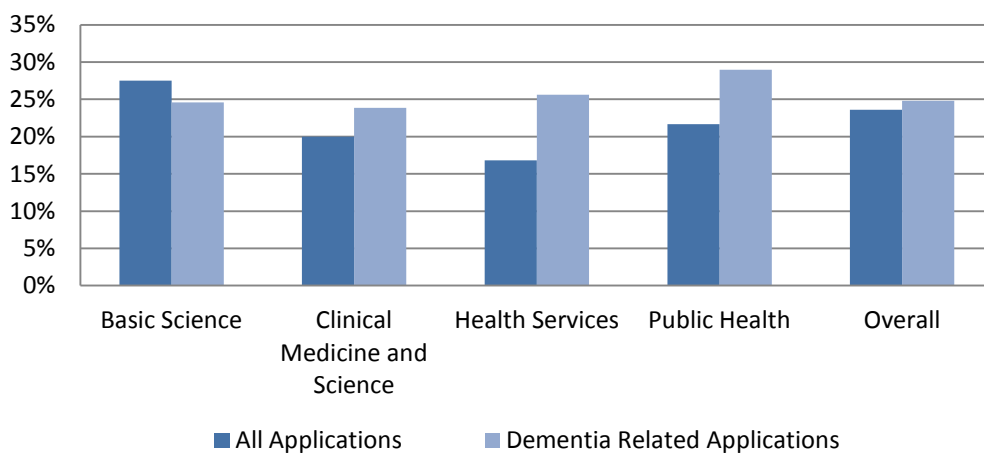


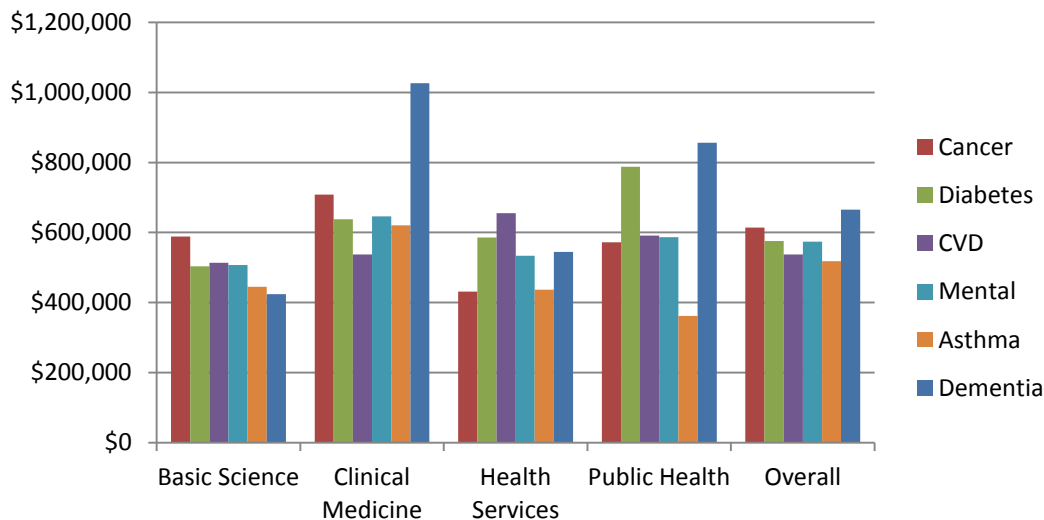
Figure 6. Average success rates 2005-2011



Value of successful dementia research funding applications

Analysis of data on NHMRC project grants over time indicates that if anything, dementia research applications have tended to be funded at a slightly higher level than project grants in other chronic disease areas (Figure 7).

Figure 7. Average Grant Commitment 2002-2011 by Broad Research Area



Number of dementia research funding applications

Between 2002 and 2011, 1068 applications were made to the NHMRC for dementia research funding across all funding streams. Of these, 262 were awarded funding. Information on the number of applications made in other fields is not publicly available.

Together, however, these figures indicate that applications for research funding being submitted by dementia researchers are competitive with those of other disciplines across most research areas, and that the low level of dementia research funding relative to other chronic disease areas is therefore a result of a low overall number of dementia research applications being submitted.

Given that the development of quality research funding applications requires significant time and expertise of investigators, it is reasonable to assume that the low volume of funding applications for dementia research reflects a lack of research capacity within the dementia field compared to other health and medical research areas.

Development of disciplinary research capacity requires accessible development pathways to allow new researchers to enter a field and establish their careers. The development opportunities for new researchers available through the NHMRC are primarily in the form of early career fellowships and career development fellowships. Analysis of publicly available

data from the NHMRC shows that the number of fellowships allocated to dementia research is substantially less than all other comparator chronic diseases apart from Asthma (see Figures 8 and 9), and that the disparity has been growing over time (see Figure 10 and 11).

Figure 8. Number of Early Career Fellowship by disease area: 2002-11

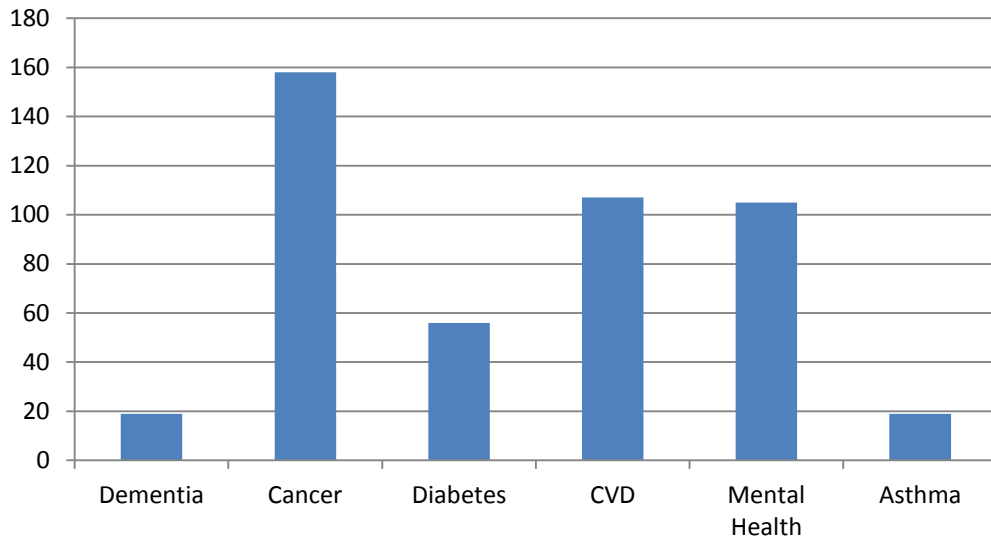


Figure 9. Number of Career Development Fellowship: 2002-11

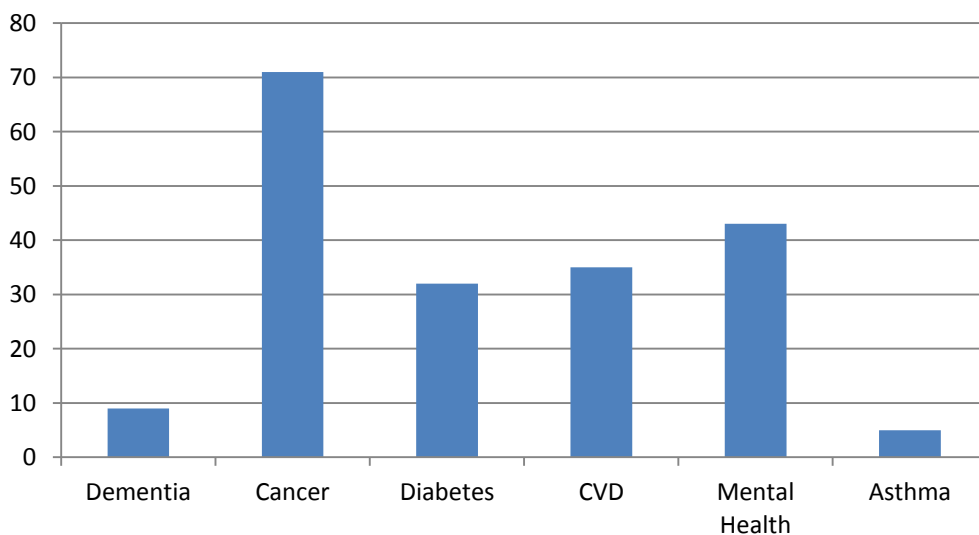


Figure 10: Early Career Fellowship commitment by disease area

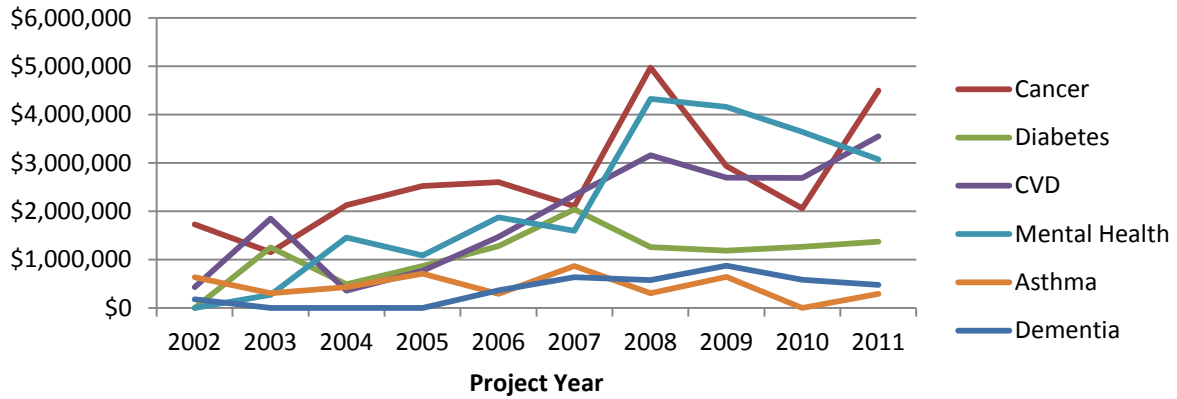
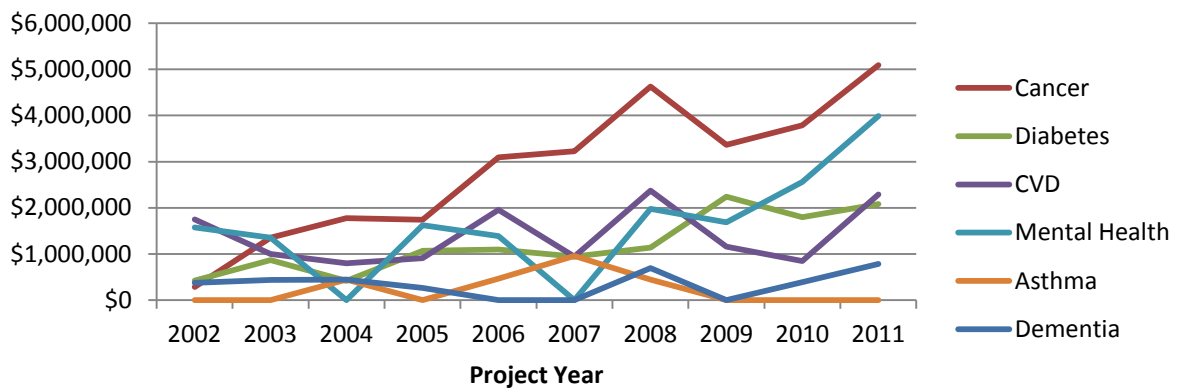


Figure 11: Career Development Fellowship commitment by disease area



In summary, the gap between capacity development funding in dementia and other chronic diseases is growing. Research training is slow, and unless there is strategic and systemic focus on building capacity in terms of people and infrastructure, the disparity in research funding will continue to expand, and it is difficult to see how there will be any change in the overall patterns of funding for dementia research as it becomes a much more critical issue facing the health and aged care system in the future.

Alzheimer's Australia has recognised this gap in research funding, and has been actively seeking to address it over a number of years through a competitive, peer-reviewed capacity building grants program for new and emerging dementia researchers. This program is funded by donations and bequests, and has grown in value from just \$60,000 a decade ago, to over \$1 million today. It has also been successful in meeting its objectives, with a number of early grant recipients going on to secure additional grants, and to establish significant careers as independent dementia researchers.¹⁶ However, much more needs to be done.

¹⁶ See www.fightdementia.org.au/research-publications/dementia-research-foundation.aspx

Recommendation 4. *That effort is made to increase research capacity in current and emerging health priorities areas such as dementia by allocating significant additional funding to boost the number of postgraduate scholarships, early career fellowships and capacity development fellowships awarded in these areas.*

4. Translating existing evidence into better health and aged care practice

In order to realise the value of the health and medical research and to promote better health outcomes for all Australians, health policy makers and health and care practitioners depend on the timely implementation of relevant health and medical research into practice.

Unfortunately, in dementia and many other areas of healthcare, the implementation of research into mainstream practice is very often fragmented or unnecessarily delayed. It is estimated, for instance, that it takes an average of 17 years between publication of new research findings and widespread uptake of recommended practice in the health and medical community.¹⁷ This results in relatively high levels of potentially avoidable chronic disease and ongoing public funding of healthcare practices that are known to be ineffective or, in some cases, harmful.

For example, a large proportion of people with dementia receive ongoing off-label treatment with potentially dangerous antipsychotic medications to control behavioural and psychological symptoms associated with dementia. This is despite solid evidence highlighting both the dangers of these medications, and the utility and efficacy of much less invasive psychosocial interventions. A recent report on this issue in the UK estimated that only 20% of the 180,000 people with dementia treated with antipsychotics derived any benefit, and attributed 1,800 avoidable deaths, and 1,620 avoidable strokes to the practice.¹⁸ Similarly, many people with end-stage dementia are hospitalised and receive invasive medical or surgical intervention such as PEG tubes or Cardio-Pulmonary Resuscitation, despite strong evidence indicating that such interventions are very often detrimental to the quality of remaining life of the individual and their family carers.¹⁹

Knowledge translation is often promoted as a way of addressing such gaps between evidence and practice, and a large number of Government, private and not-for-profit organisations, including Alzheimer's Australia, have engaged in activities aimed at fast-tracking the translation of relevant existing research evidence into improved health, medical and aged care practice. However, knowledge translation is an extremely broad term that has been used to cover everything from translational research (meta-analyses, or randomised intervention trials) through to national implementation of disease screening programs and public awareness campaigns.

In order to achieve wide-spread implementation of research into practice – for example, up-scaling a successful pilot of an evidence-based nursing intervention to facilitate diagnosis of dementia in primary care to a larger demonstration project then a national rollout – skills,

¹⁷ Balas, E. A., & Boren, S. A. (2000). Managing clinical knowledge for health care improvement. *Yearbook of Medical Informatics*, Schlattauer: 65-70

¹⁸ Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: Time for action. A report for the Minister of State for Care Services*. Department of Health, UK.

¹⁹ Lorenz, K. et al., (2008). Evidence for improving palliative care at the end of life: A systematic review. *Annals of Internal Medicine*, 153(2), 147-159.

experience, and resources are required that generally do not exist within the health and medical research sector.

What is required instead is dedicated funding, partnerships, external expertise and engagement of stakeholders including consumers, service providers, policy makers, researchers and regulators, to agree on problems and strategies, understand the barriers, the facilitators and the context, and to work together to collectively address these.

In an attempt to improve translation of research into practice in the area of dementia care, Alzheimer's Australia launched the National Quality Dementia Care Initiative in 2010 with \$3.3 million funding from the J.O. and J.R. Wicking Trust and Bupa Care Services Australia.²⁰ This program is driven by members of the CDRN and has brought together a diverse range of stakeholders to establish eight projects that will translate existing dementia care research into improved practice across Australia in areas of priority to consumers. Achieving national practice change on a limited budget is a difficult undertaking, and the program has been required to trial innovative approaches as well as spend time working with a range of stakeholders to build capacity and ensure a common understanding of what is required for effective translation of research into practice.

The NHMRC has also recently launched a Partnership Centre funding scheme with the objective of bringing together researchers with those working in the system to address critical health system issues through evidence implementation, evidence synthesis, collaborative research and capacity building. Alzheimer's Australia and the CDRN are proud to be a Funding Partner in the first of these centres: *Dealing with Cognitive and Related Functional Decline in the Elderly*. The CDRN is anticipating a central involvement over the lifetime of the centre as a consumer consultative body and through direct involvement in the work of the Centre.

Recommendation 5. *That the review panel consider the experience and the learning of organisations such as Alzheimer's Australia that have been engaged in efforts to translate existing evidence into better practice in specific areas such as dementia care*

Recommendation 6. *That the Government devote significant resources to developing new initiatives and supporting existing initiatives (such as the NHMRC Partnership Centres, and the Alzheimer's Australia National Quality Dementia Care Initiative), that are aimed at bringing together key stakeholders, including consumers, with the objective of translating existing evidence into wide-spread improvements in practice.*

²⁰ See www.fightdementia.org.au/quality-dementia-care-initiative.aspx

5. Consumer engagement in health and medical research

As the eventual beneficiaries of health and medical research, consumers – in this context, people living with health conditions, and their family carers and friends – are well positioned to provide a valuable contribution to the research effort. The potential value of this contribution to both researchers and consumers themselves has been acknowledged by various organisations and funding bodies, including the NHMRC²¹, in both Australia and overseas.

Consumers come from all walks of life and have a diverse range of personal and professional skills and backgrounds. As the direct recipients of healthcare, they are often uniquely positioned to identify specific or systematic problems with healthcare delivery that could potentially be rectified through research-based solutions. In many cases, they are also well placed to assist with or direct the dissemination and implementation of research using personal and professional networks and innovative strategies that are not easily available to researchers or health service providers. Meaningful involvement of consumers in research can also ensure that research findings are more relevant to consumers and the health and care professionals who treat them, and can add credibility to academic work that in some cases might otherwise be perceived as esoteric and removed from real world issues.

At the same time, most consumers are not well versed in the scientific method or in the language and the methodology of academic research. This means that meaningful consumer engagement in research requires careful communication and significant effort from both sides in order to achieve a common ground of understanding and trust from which to build successful engagement and collaboration.

While there are many outstanding examples of meaningful consumer engagement in research and significant enthusiasm and good will on both sides, the fact is that establishing successful engagement requires a systematic investment of time, support and expertise from all parties.

Sourcing and adequately funding these inputs within individual research endeavours is often difficult or impossible, particularly for research undertakings subject to strict funding conditions and with a focus on research-oriented deliverables. As such, consumer engagement can be significantly enhanced through the establishment of independent structures that provide a supportive framework and context for the facilitation of mutual engagement between consumers and researchers.

A supportive framework for consumer engagement in dementia research was established by Alzheimer's Australia and the Dementia Collaborative Research Centres (DCRCs) in 2010 in the form of the Consumer Dementia Research Network. The CDRN is a network of 25 individuals who either have dementia or are family members who care for or have previously cared for a person with dementia. Members have a wide range of personal and professional

²¹ Statement on Consumer and Community Participation in Health and Medical Research (2002). Available at: www.nhmrc.gov.au/guidelines/publications/r22-r23-r33-r34

backgrounds and skills, are representative of each state and territory of Australia, and representative of a range of cultural backgrounds, including Aboriginal and Torres Strait Islander backgrounds. Although the CDRN does include some members with professional experience in research and aged care, the majority of members simply have an interest in dementia research, and in working to improve the quality of dementia care through translation of research into practice.

The CDRN is broadly based on the UK Quality in Dementia Research Network and is partly supported through funding from the DCRCs. More information on the CDRN and this approach to consumer involvement is provided in Appendix B.

In reviewing the literature on structures to support consumer engagement in research as part of the development of an evaluation framework for the CDRN, the Centre for Health Service Development (CHSD), at the University of Wollongong established a list of eight key elements that are required for successful consumer engagement in research. These are:

1. **Supportive leadership and culture** – that initiates the engagement process and supports its outcomes
2. **Role clarity / governance** – clarity for consumers and researchers about expectations and contributions
3. **Resources** – including financial and informational, to support participation in the engagement process on all sides
4. **Participation** – active involvement and engagement of consumers in all aspects of the research process
5. **Capacity building** – opportunities for stakeholders on all sides to develop their skills
6. **Tailored support** – for individual stakeholders to facilitate engagement
7. **Effective communication**
8. **Recruitment and selection** – of consumers to ensure engagement of individuals with personal interest and with links to representative groups.

CHSD's report on the interim evaluation of the CDRN (included at Appendix C) emphasised that each of these elements has been critical in allowing the Network to generate an impressive list of achievements over its first 18 months of operation. These achievements include:

- Setting priorities for, and making funding decisions regarding knowledge translation projects through the Alzheimer's Australia National Quality Dementia Care Initiative;
- Working closely with the DCRCs to contribute to individual research projects, assessment of research funding applications, and to higher-level research agenda setting processes;
- Setting priority areas for research funding through the Alzheimer's Australia Dementia Research Foundation;
- Presenting to researchers and service providers at a range of research conferences and industry events;
- Establishing a relationship with the NHMRC, including facilitation of small group discussions at a joint NHMRC, Alzheimer's Australia workshop on Translating

Dementia Research into Practice (a brief report of this workshop included at Appendix D)

- Contributing to the establishment of scope and priorities for a new NHMRC Partnership Centre on *Dealing with Cognitive and Related Functional Decline in the Elderly*. When established, a member of the CDRN will join the centre team as a *Designated Systems-Based Investigator*;
- Developing this submission on the future of Australia's health and medical research system

Importantly, the CDRN is supported by Alzheimer's Australia by a dedicated Network Manager position. This employee has a research background and is responsible for facilitating opportunities for engagement and interaction between consumers and researchers, for promoting the network as a resource, and for supporting the skills and capacity development needs of both consumers and researchers to establish successful interaction and engagement. The Network is supported by Alzheimer's Australia's management and Board, and has funding to engage in capacity building and regular communication for members, including at least two face-to-face meetings each year. The interim evaluation report on the CDRN recommended that support of the Network continue to rest with Alzheimer's Australia, but that ongoing funding should be the responsibility of the Government, through the NHMRC (see Appendix C).

Recommendation 7. *That formal independent mechanisms be established for engaging consumers in all aspects of health and medical research in specific disease areas. The Consumer Dementia Research Network (CDRN) is recommended as a successful model of such a framework that could easily be implemented in other fields, with Government or other funding, and through the support of relevant consumer organisations.*

Recommendation 8. *That the NHMRC ensure ongoing funding for the CDRN through the Dementia Collaborative Research Centres or another mechanism, as recommended by the Centre for Health Service Development in their interim report on the CDRN.*

6. Conclusion

The profile of healthcare needs in Australia is changing rapidly. As a consequence of population ageing, advances in detection and treatment of many conditions, and changing patterns of exposure to risk and protective factors for many others, it is highly likely that the major demands on the health and aged care systems over the coming decades will come from complex age-related chronic conditions such as dementia.

Dementia is arguably the major chronic condition of the 21st Century. It is caused by a number of currently incurable neurodegenerative diseases, it affects almost 280,000 Australians today, and will affect almost 1 million people by mid-century.

Australian researchers have been instrumental over the past 30 years in progressing our understanding of dementia, however there is still much to learn. There are unanswered questions of the myriad causes of dementia, and we are yet to see a disease modifying drug, despite significant investment by governments and pharmaceutical companies over the past decades. Neither do we have a good grasp of the best approaches to diagnosing, managing and caring for those with the condition, or supporting those who care for them.

Health and medical researchers from Australia and abroad have succeeded over the past century in delivering better health, and adding significant years to life. However, as the population ages and dementia prevalence increases, we must increasingly focus on ensuring quality of life in these extra years by finding new ways to detect, delay, slow or prevent dementia-related cognitive decline. We also need to do more to ensure that relevant research is translated into tangible benefits and outcomes that directly improve health and well-being.

The recommendations in this submission have been developed by the CDRN; a network of consumers with a strong and personal interest in seeing that available research funding is well targeted to address priority health issues of the future, and that existing research is optimally translated into better health and care.

The Review of Health and Medical Research is a timely opportunity to ensure that these outcomes can be achieved, and the CDRN looks forward to consulting further with the Review Panel.