EVALUATION OF NHMRC DATA ON THE FUNDING OF DEMENTIA RESEARCH IN AUSTRALIA

A REPORT FOR ALZHEIMER’S AUSTRALIA

PAPER 26

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INTRODUCTION

The aim of this report is to provide the evidence base for evaluating the level of expenditure by the National Health and Medical Research Council (NHMRC) on research funding (including research, people support and infrastructure) related to dementia, in comparison to research funding for other areas of chronic disease. The report was commissioned by Alzheimer’s Australia to support a submission to the McKeon Review of Health and Medical Research in Australia in March, 2012.

WHY RESTRICT TO NHMRC FUNDING?

There are several sources of research funding for dementia in Australia. These include the Alzheimer’s Australia Dementia Research Foundation, the J.O. and J.R. Wicking Trust, The Australian Research Council, the NHMRC, and other State and Territory Government and Non-Government Organisations. However, the NHMRC is the largest and most significant source of funding for health and medical research, and the only single institution that provides all the different types of funding for research (projects, centres, programmes, partnerships), research infrastructure and training and people. Evaluation of NHMRC data also allows for a direct comparison between funding for dementia research, and funding for research into other areas of chronic disease. NHMRC funding history is also publically available and accessible via the internet at the level of detail that allows for statistical evaluation. Whilst we acknowledge therefore that our analysis of NHMRC funding does not provide the full picture of dementia research funding in Australia, it still evaluates the most significant source of funding for dementia research.

A limitation of using only NHMRC data for comparing chronic disease areas, is that it may underestimate the difference in the total amount of research funding for dementia compared with the total funding for research in Cardiovascular Disease, Mental Health, Diabetes and Cancer because most of these disease areas have larger Foundations (e.g. the Heart Foundation, Diabetes Australia, Cancer Council), and Mental Health has received a significant amount of funding from the beyondBlue initiative.

METHODS

Data sources
The analyses were conducted using publically available data on research funding for the current decade and were downloaded from the NHMRC website on 1/2/2012.

In addition, NHMRC provided data in confidence on all applications from 2002 to 2011 for grants that were identified as related to dementia. This data identified the funding status (‘funded’ vs. ‘not funded’), and fundability (‘fundable’ vs. ‘not fundable’) of each grant application. These data were used to evaluate the success rates of research grants on dementia compared to grants funded in other chronic disease areas.

Chronic Disease Identification Using Keywords
Grant applications in the public dataset were classified as being related to one (or more) of six chronic disease types, namely: Dementia, Cancer, Cardiovascular Disease (CVD), Mental health, Diabetes, Asthma. The keywords used to identify disease related grant applications are listed in Table 1. The fields from the worksheet “Data Source 2002 to 2011” used to search for keywords were: Scientific Title, Simplified Title, Research Keywords (1-5), Health Keywords (1-5), and Research Field. It was possible for applications to be identified as related to more than one disease group. Before the keyword search was conducted, all text was converted to lowercase. All data coding and analyses were conducted with STATA version 10 statistical software.
Table 1: Keywords used to identify disease related grant applications.

<table>
<thead>
<tr>
<th>Disease</th>
<th>Keywords</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia</td>
<td>dementia, alzheimer*, &quot;mild cognitive impairment&quot;</td>
</tr>
<tr>
<td>Cancer</td>
<td>cancer, oncolo*, carcino*, neoplasm, tumor, tumour, malignant</td>
</tr>
<tr>
<td>Mental health</td>
<td>mental, psycho*, psychi*, impulsive, fear, anxiety, panic, stress, compulsive, anorexia, bulimia, “eating disorder”, schizophren*, depress*</td>
</tr>
<tr>
<td>Diabetes</td>
<td>diabet*, hyperglycemia, “blood sugar”, hyperglycaemia, hyperinsulinemia</td>
</tr>
<tr>
<td>Asthma</td>
<td>asthma, “inflammatory disorder of the airways”, wheezing, “laboured breathing”, “narrowed air passage”</td>
</tr>
</tbody>
</table>

Note: “oxidative stress” was an exclusion term for identifying Mental Health related project applications

Funding 2002-2011
Funding commitment and funding expenditure for each disease group were calculated from the public dataset. These were calculated by project year, Broad Research Area (Basic Science, Clinical Medicine, Public Health, and Health Services), Main Funding Group (Infrastructure, People Support, and Research Support), Funding Purpose and Funding Scheme.

Dementia Related Application Success Rates
Success rates for dementia related grant applications were calculated using the data provided in confidence by the NHMRC. These were calculated by application year, Broad Research Area, Funding Purpose and Funding Scheme. Dementia application success rates were compared to overall success rates listed publicly on the NHMRC website at http://www.nhmrc.gov.au/grants/research-funding-statistics-and-data/summary-funding-data/nhmrc-project-grants-success-rate-b

Validation of Classification of Disease Related Projects
A Delphi study was conducted to assess the accuracy of the keywords used to identify disease related grant applications. Four blinded experts reviewed a random sample of 4% (n=109) of projects that commenced after 2006 and were identified as being disease-related by the automated keyword search. The random sample included equal proportions for each disease classification. The experts rated each project as ‘disease specific’, ‘disease related’ and ‘unrelated to disease’. Agreement amongst expert ratings were used as an indicator of the accuracy of the method used to categorise disease related grants.

Further sensitivity analyses were conducted for the identification of dementia related projects. Keywords were expanded to include ‘brain ageing’, ‘brain aging’, ‘parkinson*’, and ‘cognitive decline’. Results were also compared to findings based on searches that were restricted to keywords found only in the scientific title and research keywords fields.
Results

1. Total Amount of Funding and Total Number of Project Grants

Between 2002 and 2011 there were 10,196 funded grant applications and 11,102 grant projects or fellowships commenced. In this time 4,580 funded or commencing grants were identified as related to one of the six disease categories. From 2002 to 2011, the total commitment to dementia research was $169,771,557, compared to $1,077,307,726 for cancer, $415,265,321 for diabetes, $542,144,243 for CVD, $121,651,064 for asthma and $636,535,741 for mental health. This is reflected in the lower number of project grants in dementia over the same period (Table 1).

Table 1: NHMRC project funding by disease type for projects starting during 2002-2011

<table>
<thead>
<tr>
<th>Chronic Disease Area</th>
<th>Number of Projects</th>
<th>Total Commitment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia</td>
<td>255</td>
<td>$169,771,557</td>
</tr>
<tr>
<td>Cancer</td>
<td>1753</td>
<td>$1,077,307,726</td>
</tr>
<tr>
<td>Diabetes</td>
<td>722</td>
<td>$415,265,321</td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td>1009</td>
<td>$542,144,243</td>
</tr>
<tr>
<td>Mental health</td>
<td>1109</td>
<td>$636,535,741</td>
</tr>
<tr>
<td>Asthma</td>
<td>235</td>
<td>$121,651,064</td>
</tr>
</tbody>
</table>

Note: Double counts were checked as some grants fall in multiple categories. There were 26 projects identified as both Mental Health and Dementia related (10.2% of dementia projects); 6 projects identified as both CVD and Dementia related (2.3% of dementia projects); 12 projects identified as both Diabetes and Dementia related (4.7% of dementia projects); 10 projects identified as both CVD and Dementia related (3.9% of dementia projects).
2. OVERALL FUNDING COMMITMENT AND EXPENDITURE BY CHRONIC DISEASE, 2002-2011

The graphs below illustrate that funding for dementia research does not show the rate of increase that is evident for other disease categories (although Diabetes shows a reduction in funding over the past two years). This means that the disadvantage of dementia research compounded over time until 2011. There was an increase in funding in 2011. Data in future years will enable evaluation of whether this is a genuine upwards trend.
3. OVERALL FUNDING COMMITMENT 2002-2011 BY BROAD RESEARCH AREA

**Basic Science**

- Dementia: $350,000,000
- Cancer: $300,000,000
- Diabetes: $250,000,000
- CVD: $200,000,000
- Mental Health: $150,000,000
- Asthma: $100,000,000

**Clinical Medicine and Science**

- Dementia: $250,000,000
- Cancer: $200,000,000
- Diabetes: $150,000,000
- CVD: $100,000,000
- Mental Health: $50,000,000
- Asthma: $0

**Health Services Research**

- Dementia: $50,000,000
- Cancer: $40,000,000
- Diabetes: $30,000,000
- CVD: $20,000,000
- Mental Health: $10,000,000
- Asthma: $0

**Public Health**

- Dementia: $260,000,000
- Cancer: $200,000,000
- Diabetes: $150,000,000
- CVD: $100,000,000
- Mental Health: $50,000,000
- Asthma: $0
Health services research is the only area where dementia is on par with diabetes and heart disease. Public health funding for dementia is at a particularly low level.
There was no funding for infrastructure for dementia over the study period. We are unclear what “External funding” refers to and whether the Dementia Collaborative Research Centres are included in this. It is the only area where dementia is has more funding than other areas.
5. OVERALL FUNDING COMMITMENT 2002-2011
BY RESEARCH GROUP

**Capacity – Facilities**

- Dementia: $35,000,000
- Cancer: $30,000,000
- Diabetes: $25,000,000
- CVD: $20,000,000
- Mental Health: $15,000,000
- Asthma: $10,000,000
- $5,000,000
- $0

**People Support**

- Dementia: $250,000,000
- Cancer: $200,000,000
- Diabetes: $150,000,000
- CVD: $100,000,000
- Mental Health: $50,000,000
- Asthma: $0

**Research Support**

- Dementia: $800,000,000
- Cancer: $600,000,000
- Diabetes: $400,000,000
- CVD: $200,000,000
- Mental Health: $200,000,000
- Asthma: $0

Alzheimer's Australia
6. OVERALL FUNDING COMMITMENT 2002-2011 BY SCHEME (SELECTED)
7. ANALYSES BASED ON CONFIDENTIAL NHMRC DATA

Success Rates 2005 – 2011

- Basic Science
- Clinical Medicine and Science
- Health Services
- Public Health
- Overall

Success Rates by Year of Application

- All applications
- Dementia applications

Total Dementia Applications 2005 – 2011

- Proportion of dementia applications
- Number of dementia applications

All applications
Dementia related applications
Evaluation of NHMRC Data on the Funding of Dementia Research in Australia

**Basic Science Success Rates by Year of Application**

- All applications
- Dementia applications

**Clinical Medical and Science Success Rates by Year of Application**

- All applications
- Dementia applications

**Health Services Grants Success Rates by Year of Application**

- All applications
- Dementia applications

Note: there were only 2 applications in 2005 identified as dementia related health services projects. There were fewer than 15 dementia related applications every year except 2007.
Methodological checks of our analysis
To evaluate the coding of project grants a small Delphi study was conducted by 4 experienced researchers including 2 Research Fellows from the Dementia Collaborative Research Centre. Each researcher was asked to classify 109 projects selected at random from the NHMRC spreadsheet, into 6 disease categories. These included dementia, cancer, diabetes, cardiovascular disease, mental health and asthma. For each study, each rater indicated if the project was
- directly related or disease specific (e.g. dementia is the clearly the main focus and outcome of a study)
- peripherally related or disease general (e.g. dementia is a contextual variable but not the focus of the study)
- unrelated (e.g. dementia is not related to the project aims).

Results
There was strong agreement across expert ratings and with keyword search. Experts reached total consensus for 95% of the dementia grants reviewed, compared to 89% for Cancer, 95% for Diabetes, 100% for Cardiovascular Disease, 50% for Mental Health and 83% for Asthma.

Consensus was not reached for one dementia grant, and experts unanimously disagreed with the keyword search for one other dementia grant. Both these grants were Basic Science projects that were not directly nor specifically related to dementia research, but identified either ‘Alzheimer’s Disease’ or ‘dementia’ as health keywords.

There was a low level of agreement among experts on what constituted a mental health related project. Further, a number of non-mental health projects were identified by ‘mental’ as a suffix within the terms ‘environmental’ or ‘developmental’. Some of these projects were still rated as mental health projects by some experts – highlighting the difficulty in defining and categorising mental health projects.

Sensitivity Analysis
When keywords were expanded to include ‘brain ageing’, ‘brain aging’, ‘parkinson*’, and ‘cognitive decline’, the number of projects identified as relating to dementia increased from 255 to 350 with a total funding commitment of $212,363,142. All additional studies were identified by the keyword ‘parkinson*’. When the search was restricted to projects with keywords found only the scientific title and research keyword fields (excluding the health keyword field), 199 dementia specific projects were identified with a total funding commitment of $144,549,818.

In comparison, restricting the search fields for other chronic diseases revealed 1,360 Cancer specific projects ($867,747,453), 721 diabetes specific projects ($415,265,321) and 889 CVD specific projects ($483,613,070).

When ‘mental’ was expanded as a keyword to ‘mental health’ there were only 903 grants identified, with a total commitment of $518,024,553. It is notable that ‘mental’ is listed as a keyword used by the NHMRC to identify mental health related projects in publicly available datasets.
SUMMARY OF KEY OUTCOMES

This analysis of research funding according to chronic disease demonstrates that funding for dementia research lags far behind Cancer, Diabetes, Cardiovascular Disease and Mental Health. Overall funding levels for dementia are similar to those for Asthma. The differentials in funding are evident across all funding types.

There were fewer project grants for dementia than in all areas except for asthma. The ratio of dementia grants to other chronic disease grants was:

- dementia: mental health = 1: 4.3
- dementia : cancer = 1: 6.9
- dementia : diabetes = 1: 2.8
- dementia : CVD = 1: 3.5
- dementia : asthma = 1: 0.9

Both overall expenditure and overall commitment of funding from 2002-2011 were low for dementia relative to the other chronic disease areas except for asthma. Importantly, funding for dementia showed very little increase over the time period, in comparison to funding on the other chronic disease areas. This has meant that since 2002, the difference in funding levels for dementia versus diabetes, cancer, CVD and mental health, has grown significantly.

Relatively lower rates of funding for dementia are not restricted to any specific area. There has been far less funding for dementia than other chronic disease areas (except asthma) in basic science, clinical medicine and science, health services and public health. Despite massive increases in funding for basic science funding for cancer research, and moderate increases in diabetes, CVD and mental health, there has been only a slight increase in funding for basic science research in dementia. Similarly dementia and asthma research in clinical medicine has shown very little increase unlike the other chronic disease areas.

An increase in dementia research funding in the area of health services was seen from 2007 to 2011 so that health services research is the only domain where dementia research funding is on a par with diabetes and cancer. The largest increase in health services funding has been in mental health and this chronic disease area has received the most funding in health services for the entire study period (2002-2011). Similarly, mental health has received the most funding in public health since 2002 and dementia has received a very low rate of funding that has not increased.

Dementia and asthma research received no funding in Capacity-facilities, and CVD received a minimal amount of funding in this area. This is compared to nearly $30 million in cancer, and $10 million in mental health. In terms of people support, dementia again lags behind all other major disease categories except for asthma. It received $25,632,057 compared to $207,525,648 in Cancer, $82,020,491 in diabetes, $94,072,037 in CVD and $122,423,636 in mental health. Dementia lagged behind all other chronic disease areas in funding for translational research.

When comparing grant type, the picture remained consistent. The number of project grants, program grants, Centres for Research Excellence and Fellowships in dementia and asthma is lower in all areas, with dementia and asthma receiving the lowest amount of funding in different categories. The size of the difference in funding between dementia and asthma and the other chronic disease categories, was substantial. For example, when all fellowships were examined, funding for dementia was $24,304,203 versus $93,151,484 in mental health, and $187,631,059 in cancer. Lower funding rates for dementia and asthma were seen in fellowships at all career stages, indicating that without an injection of funding, there is not going to be an increase through natural development of researchers through the NHMRC Fellowships scheme. This is confirmed by examining funding committed for NHMRC Fellowships. There is a small increase in committed funds for 2011, but dementia and asthma remain far lower than the other areas. From 2002 to 2010 there was virtually no increase in committed funding for people support in dementia, while committed funding increased dramatically in the areas of cancer, diabetes, CVD and mental health.

Overall this suggests a major problem of research capacity in dementia research. Without people, there is no one to apply for project or program grants. This is a systemic problem that requires a strategic and systemic approach to fix it. Of particular concern are the figures for committed funds for early career fellowships. Here we see no increase in the low funds committed for dementia, compared to far higher commitments in the other areas, with large increases in cancer, diabetes and CVD. This must reflect a lack of junior academics applying for fellowships in the dementia field, as there is no bias in the success rates against dementia research. A priority for the future must therefore be to increase the attractiveness of dementia research to young scientists.

Confidential data from NHMRC on success rates.

Evaluation of the success rates of grants was conducted across five research areas. Dementia research grants had higher success rates in clinical medicine and science, health services and public health, but lower rates in basic science. It is unclear if these rates include the strategic funding for the Dementia Research Grants which would have raised the success rates. These figures show that the quality of research proposals being submitted in dementia are sufficiently high to be funded and there is no systematic bias in the success rates that could explain the lower overall funding for dementia. This indicates that the lack of research funding in this area is due to capacity, i.e., a lower number of applications being submitted, due to fewer people with the skills to conduct high quality research in the field of dementia in Australia.
Conclusion
Dementia research funding in Australia is significantly underfunded compared with other chronic disease areas that place equally large (or less) demand on the health system. Analyses of the publicly available NHMRC data indicate this is a systemic problem across all domains of research funding. Unless there is strategic and systemic direction of funding to build capacity in terms of people and infrastructure, it is difficult to see how change in the patterns of funding for dementia will occur. Research training is slow and it will take 5-10 years to develop a new cohort of researchers in dementia. Researchers need to be attracted into the field of dementia – it is possible that other areas of chronic disease have appeared more attractive and to offer better career opportunities to graduate students. To reverse current trends, dementia research needs to develop the necessary infrastructure and career paths to attract and retain top graduates and postdoctoral fellows. Strategic funding of dementia research in terms of allocation of dementia specific fellowships, infrastructure and research funding needs to become a priority for NHMRC.
Quality Dementia Care Series
1. Practice in Residential Aged Care Facilities, for all Staff
2. Practice for Managers in Residential Aged Care Facilities
3. Nurturing the Heart: creativity, art therapy and dementia
4. Understanding Younger Onset Dementia
5. Younger Onset Dementia, a practical guide
6. Understanding Dementia Care and Sexuality in Residential Facilities
7. No time like the present: the importance of a timely dementia diagnosis

Papers
1. Dementia: A Major Health Problem for Australia. September 2001
2. Quality Dementia Care, February 2003
3. Dementia Care and the Built Environment, June 2004
5. Legal Planning and Dementia. April 2005
6. Dementia: Can It Be Prevented? August 2005 (superceded by paper 13)
7. Palliative Care and Dementia. February 2006
9. 100 Years of Alzheimer's: Towards a World without Dementia. August 2006
17. Respite Care for People Living with Dementia. May 2009
18. Dementia: Facing the Epidemic. Presentation by Professor Constantine Lyketsos. September 2009
20. Ethical Issues and Decision-Making in Dementia Care. Presentation by Dr Julian Hughes. June 2010

22. Consumer Involvement in Dementia Research September 2010
24. Timely Diagnosis of Dementia: Can we do better? September 2011
25. National Strategies to Address Dementia, October 2011

Reports commissioned from Access Economics
The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, March 2003
Delaying the Onset of Alzheimer’s Disease: Projections and Issues, August 2004
Dementia Estimates and Projections: Australian States and Territories, February 2005
Dementia in the Asia Pacific Region: The Epidemic is Here, September 2006
Dementia Prevalence and Incidence Among Australian’s Who Do Not Speak English at Home, November 2006
Making choices: Future dementia care: projections, problems and preferences, April 2009
Keeping dementia front of mind: incidence and prevalence 2009-2050, August 2009
Caring places: planning for aged care and dementia 2010-2050. July 2010
Dementia Across Australia 2010-2050. September 2011

Other Papers
Dementia Research: A Vision for Australia September 2004
National Consumer Summit on Dementia Communique, October 2005
Mind Your Mind: A Users Guide to Dementia Risk Reduction 2006
Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities, November 2006
National Dementia Manifesto 2007-2010
Dementia: A Major Health Problem for Indigenous People August 2007
In Our Own Words, Younger Onset Dementia, February 2009
National Consumer Summit Younger Onset Dementia Communique, February 2009
Dementia: Facing the Epidemic. A vision for a world class dementia care system. September 2009

These documents and others available on www.alzheimers.org.au
VISIT THE ALZHEIMER’S AUSTRALIA WEBSITE AT
WWW.FIGHTDEMENTIA.ORG.AU

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DEMENTIA AND CARE
INFORMATION, EDUCATION AND TRAINING
OTHER SERVICES OFFERED BY
MEMBER ORGANISATIONS

OR FOR INFORMATION AND ADVICE CONTACT
THE NATIONAL DEMENTIA HELPLINE ON

1800 100 500
(National Dementia Helpline is an Australian Government funded initiative)