Summary Document

NHMRC Dementia Research and Translation Priority Setting Project
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Introduction

The purpose of the national dementia research and translation priorities

What are the national dementia research and translation priorities that will optimise outcomes across the domains of prevention, treatment, diagnosis and care?

Dementia is recognised globally as a public health priority. In 2012 dementia was declared the ninth Australian National Health Priority Area. As part of the 2014-15 Budget, the Australian Government announced $200 million over five years to boost research to improve prevention, diagnosis, treatment and care in Australia.

In the context of these decisions, this project aims to establish a set of national research and translation priorities that will optimise outcomes across the domains of prevention, treatment, diagnosis and care that will inform NHMRC strategic funding decisions. The research and translation priorities have been informed by the following line of enquiry:

**Insights:** what is the current experience of people with dementia and their carers in Australia? Are they receiving best practice care informed by international and Australian research? Where are their pain points? Can Australian health and care services be improved by adopting best practice research? What are the research priorities people with dementia and their carers consider to be the most important now and for the future?

**Themes:** What are the key themes that will optimise research outcomes in the areas of prevention, treatment, diagnosis and care now and into the future? Informed by researchers and clinical practitioners.

**Actions:** What are the actions needed to optimise the outcome for each theme?

**Outcomes:** What is the change we want to see? What are the likely short, medium and long term outcomes?

**Strategy:** What strategies are needed to enable research and translation to optimise outcomes? Informed by researchers and medical practitioners
Our process

The purpose of this project was to conduct a stakeholder consultation process to understand the research priorities from multiple perspectives.

- Consumers (people with the lived experience of dementia, their family and personal carers) informed an understanding of the current experience of dementia from pre-diagnosis to end of life care, creating an awareness of significant gaps and barriers to translating research knowledge into practice
- Researchers (basic, clinical and applied, across the domains of prevention, treatment, diagnosis and care) provided insight into the strengths in Australian research and the barriers to optimising outcomes
- Medical practitioners informed an understanding of the current service delivery and approaches to care from diagnosis to end of life care in multiple care settings including primary and acute care
- Aged care providers informed an understanding of current models of aged care and challenges and opportunities as experienced by care providers

Stakeholders were engaged through exploratory interviews and focus groups to develop insights about the current experience of living with dementia, care provision, medical practice and research and translation in Australia.

National survey

Insights from this initial engagement informed a national survey which asked participants to prioritise research objectives that would optimise outcomes for people with dementia now and into the future.

Participants

We conducted focus groups and interviews in New South Wales, Victoria, Queensland, Western Australia and the Australian Capital Territory. A breakdown of participants is below:

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Focus groups</th>
<th>Interviews</th>
<th>National survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumers and aged care providers</td>
<td>3 focus groups 13 participants</td>
<td>30 interviews</td>
<td>187 respondents</td>
</tr>
<tr>
<td>Researchers and medical practitioners</td>
<td>9 focus groups 52 participants</td>
<td>16 interviews</td>
<td>201 respondents</td>
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</tbody>
</table>
There is a **strong alignment** between the **top five priorities of key stakeholder groups** in the national survey.

The diagnosis priority for people with dementia indicates the extent to which diagnosis is currently a pain point for people with dementia. The priority for prevention indicates a consensus and confidence that research into risk and preventative factors will have an impact in reducing the incidence of dementia and is the first priority for Australian research.

There is consistency in the priority to invest in high risk exploratory research that may offer new effective interventions to treat or delay the onset of dementia in the future. The immediate short term priority for care is to improve interventions for the behavioural and psychological symptoms of dementia. This aligns with international priorities and will have significant impacts for the dignity of people with dementia and the capacity of carers to care in all environments: acute care, residential care and care in the community.

Optimising the self determination of people with dementia sits at the heart of developing effective person centred care by increasing understanding of the needs, experience and capacity of people with dementia and improving approaches to communication between people with dementia, their families and professional carers at all stages and in all contexts of care.

<table>
<thead>
<tr>
<th>People with the lived experience of dementia</th>
<th>Personal carer of a person with dementia</th>
<th>Professional care provider</th>
<th>Top priorities of senior investigators</th>
<th>Top priorities of research and medical practice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong> Optimise timely, accurate and supported diagnosis</td>
<td>Develop effective interventions to support carers and optimise their opportunity and capacity to care</td>
<td>Identify effective interventions to reduce the risk of dementia and prevent incidence of dementia</td>
<td>Identify effective interventions to reduce the risk of dementia and prevent incidence of dementia</td>
<td>Identify effective interventions to reduce the risk of dementia and prevent incidence of dementia Delay the onset</td>
</tr>
<tr>
<td><strong>2</strong> Identify effective interventions to reduce the risk of dementia and prevent incidence of dementia</td>
<td>Identify effective interventions to reduce the risk of dementia and prevent incidence of dementia</td>
<td>Optimise the development of new interventions to offer treatment or delay the onset of Alzheimer’s disease and other forms of dementia</td>
<td>Optimise the development of new interventions to offer treatment or delay the onset of Alzheimer’s disease and other forms of dementia Delay the onset</td>
<td>Optimise the development of new interventions to offer treatment or delay the onset of Alzheimer’s disease and other forms of dementia</td>
</tr>
<tr>
<td><strong>3</strong> Optimise the development of new interventions to offer treatment or delay the onset of Alzheimer’s disease and other forms of dementia</td>
<td>Optimise the development of new interventions to offer treatment or delay the onset of Alzheimer’s disease and other forms of dementia</td>
<td>Improve interventions for the behavioural and psychological symptoms of dementia to support quality of life and quality of care</td>
<td>Optimise timely, accurate and supported diagnosis</td>
<td>Optimise clinical care for people with dementia in complex care settings and at different stages of the disease</td>
</tr>
<tr>
<td><strong>4</strong> Increase the self determination and independence of a person with dementia</td>
<td>Optimise timely, accurate and supported diagnosis</td>
<td>Optimise timely, accurate and supported diagnosis</td>
<td>Improve interventions for the behavioural and psychological symptoms of dementia to support quality of life and quality of care</td>
<td>Optimise timely, accurate and supported diagnosis</td>
</tr>
<tr>
<td><strong>5</strong> Optimise clinical care for people with dementia in complex care settings and at different stages of the disease</td>
<td>Optimise clinical care for people with dementia in complex care settings and at different stages of the disease</td>
<td>Increase the self determination and independence of a person with dementia</td>
<td>Increase the self determination and independence of a person with dementia</td>
<td>Improve interventions for the behavioural and psychological symptoms of dementia (BPSD) to support quality of life and quality of care</td>
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Sketch: Stakeholder proposed strategy for dementia research and translation priorities

Today

- **289,000 people** living with dementia
- **23,900** early onset
- **1.5 million carers**

*We can make significant improvements in care and diagnosis today*

**The change we can make today**

- **IDENTIFY EFFECTIVE INTERVENTIONS**
  - Identify effective interventions to reduce the risk of dementia and prevent the incidence of dementia
- **UNDERSTAND DISEASE ORIGINS AND MECHANISMS**
  - Basic science to understand the origins and mechanisms of Alzheimer's and other forms of dementia to inform strategies for new interventions to treat or delay onset of dementia
- **Optimise timely, accurate and supported diagnosis**
- **Build an evidence base to inform best practice care (BPSD, self determination, optimal clinical care)**

2020

- **400,000 people** living with dementia

*What is likely by 2020*

- **PUBLIC HEALTH STRATEGY**
  - A public health strategy is implemented to create awareness about dementia risk and prevention: Increased awareness of risk and prevention informs treatments and interventions to prevent dementia
- **NEW TREATMENTS AND INTERVENTIONS**
  - New treatments and interventions are in development: Increased awareness of risk and prevention informs treatments and interventions to prevent dementia
- **IMPROVED EARLY DETECTION, ACCURACY AND ACCESSIBILITY**
  - There is improved early detection of dementia and improved accuracy and accessibility of diagnosis
- **IMPLEMENT SYSTEMIC CHANGE TO CARE SERVICES AND POLICY**
  - Translate systemic evidence for best practice to inform policy and service change

2030

- **550,200 people** living with dementia

*What is likely by 2025-30*

- **The incidence of dementia is reduced as a consequence of a coordinated strategy**
- **We have new, innovative treatments to delay or prevent Alzheimer’s and other forms of dementia**
- **CONTINUOUS IMPROVEMENT**
  - There is continuous improvement of accurate, timely, and early diagnosis
- **CONTINUOUS IMPROVEMENT**
  - Monitor and improve standards of care. Dementia aware and supportive environments are standard

*Australian Institute of Health and Welfare, Dementia in Australia, 2012, p. 11-19*
Stakeholder proposed strategies to optimise research and translation outcomes

Strategies for all domains of research and translation (prevention, treatment, diagnosis and care) include:

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Description</th>
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<tbody>
<tr>
<td>Designated funding</td>
<td>Designated funding for each domain prevention, treatment, diagnosis and care to build capability and enable breakthroughs in each interdependent area</td>
</tr>
<tr>
<td>Increase education and training</td>
<td>In the areas of diagnosis and care, a lack of awareness, education and training by health professionals and paraprofessionals inhibits the translation of research into practice</td>
</tr>
<tr>
<td>Build capacity</td>
<td>There is a need to build capacity in dementia research and attract outstanding early career researchers</td>
</tr>
<tr>
<td>National dementia register</td>
<td>A dementia register for everyone diagnosed with dementia to participate in research</td>
</tr>
<tr>
<td>Increase understanding of the experience of dementia</td>
<td>Understand more about the needs and impacts of dementia in different Australian populations including: ATSI and CALD populations to ensure that their needs are met</td>
</tr>
<tr>
<td>Better collaboration</td>
<td>Improved collaboration between basic science, clinical and applied research</td>
</tr>
<tr>
<td>Better coordination</td>
<td>Better coordination between Australian and international research in all domains</td>
</tr>
</tbody>
</table>
Strategies by domain include:

<table>
<thead>
<tr>
<th>Domain</th>
<th>Strategies to optimise outcomes</th>
</tr>
</thead>
</table>
| Prevention | Coordination with international research  
Increase multi-disciplinary collaboration  
Better data sharing  
Establish (or leverage existing) nation-wide longitudinal studies covering a broad population cohort, starting well before the beginning of neurodegenerative changes through to end of life, with long term objectives  
Improve data linkages to ensure high quality clinical data is available to inform research programs  
Ensure research conducted in Australia has international relevance |
| Diagnosis | Coordination with international research  
Partner with medical practitioners, allied health professionals, service providers and with people with dementia to inform systemic change  
Earlier and more thorough dementia specific training of health professionals, especially general practitioners |
| Treatment | Continue to invest in basic research to increase understanding of the complexity of dementia  
Promote tissue donation, including to the brain bank, at end of life  
Develop a National clinical dementia registry  
Support for brain bank infrastructure  
Fund innovative, novel and high risk science |
| Care | Programmes of research in care  
Grant funding that supports research in complex environments  
Research lead by outstanding nurses and allied health professionals in complex care environments  
Research and translation partnerships with care providers, government departments and with people with dementia to inform systemic change |
<table>
<thead>
<tr>
<th>Theme</th>
<th>Actions</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PREVENTION</strong>&lt;br&gt;Identify effective interventions to reduce the risk of dementia and prevent the incidence of dementia</td>
<td>- Expand our understanding of lifestyle, psychosocial and demographic risk factors&lt;br&gt; - Understand how risk factors and preventative interventions change over the life span&lt;br&gt; - Develop preventative strategies for different types of dementia&lt;br&gt; - Coordinate with basic research</td>
<td>- There is sufficient evidence to inform a public health strategy about risk and prevention for dementia&lt;br&gt; - There is increased community awareness about dementia risk factors&lt;br&gt; - Increased knowledge about risk and prevention informs new interventions for prevention and approaches to treatment</td>
</tr>
<tr>
<td><strong>TREATMENT</strong>&lt;br&gt;Optimise the development of new interventions to offer treatment or delay the onset of Alzheimer’s disease and other forms of dementia</td>
<td>- Understand the origin and disease mechanisms of different types of dementia&lt;br&gt; - Identify new pathways and targets for therapeutic interventions&lt;br&gt; - Identify the optimal time-window for interventions&lt;br&gt; - Expand understanding of genetic and environmental risk factors&lt;br&gt; - Promote innovative approaches and new technologies for prevention, treatment and rehabilitation&lt;br&gt; - Develop better, more valid, preclinical animal models of different types of dementia</td>
<td>- There is increased understanding of the complexity of dementia including the origin and disease mechanisms of different types of dementia&lt;br&gt; - There is increased understanding of risk factors and optimal timing for intervention&lt;br&gt; - Increased understanding of the disease and innovative approaches to inform the development of new interventions and treatment</td>
</tr>
<tr>
<td><strong>DIAGNOSIS</strong>&lt;br&gt;Optimise timely, accurate and supported diagnosis</td>
<td>- Refine assessment of early symptoms and function to support clinical diagnosis&lt;br&gt; - Determine the need and mechanisms for identifying people at risk, including people at risk of developing a preventable dementia&lt;br&gt; - Standardise existing biomarkers (molecular, imaging, functional and cognitive) to inform more accurate diagnosis</td>
<td>- There is a holistic framework for diagnosis that significantly improves the experience of diagnosis for the person with dementia and their family&lt;br&gt; - Social, cultural, economic and diverse need groups that are vulnerable to under diagnosis are identified, and approaches to improve the effectiveness of diagnosis for these groups are developed&lt;br&gt; - The accuracy of assessment and diagnosis are improved</td>
</tr>
<tr>
<td><strong>CARE</strong>&lt;br&gt;Develop an evidence base for approaches to care that are effective for people with dementia, optimise quality of life, support the carer and are viable for systemic implementation</td>
<td>Improve interventions for the behavioural and psychological symptoms of dementia to support quality of life and quality of care&lt;br&gt; - Increase the self determination and independence of a person with dementia&lt;br&gt;</td>
<td>- There is an evidenced based approach to managing the behavioural and psychological symptoms of dementia to support the dignity and quality of life of a person with dementia, quality of care and the wellbeing of the carer&lt;br&gt; - Pharmacological and non pharmacological interventions are optimised to improve quality of life and quality of care&lt;br&gt; - Dementia friendly environments that reduce behavioural and psychological symptoms of dementia are promoted&lt;br&gt; - The impacts of behavioural and psychological symptoms of dementia on care providers are understood and supported&lt;br&gt;</td>
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</tbody>
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