

# NHMRC National Institute for Dementia Research

Strategic Roadmap

June 2016 (Updated July 2017)



**Australian Government**

**NHMRC National Institute for Dementia Research**

# NHMRC National Institute for Dementia Research (NNIDR)

## Strategic Roadmap

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### 1. Context

Dementia is a major health problem and will soon be one of the most prevalent and devastating diseases in Australia <sup>1</sup>.

A robust, national, evidence-based and long-term approach to the diagnosis and treatment of dementia is essential to the social and economic well-being of Australia. An appropriately constructed and targeted research and translation strategy will underpin, and drive the delivery of better treatments, more effective health service delivery and intervention design thus improving the lives of those with dementia, their carers and their families. Even more importantly, fundamental research can help us understand the cause of dementia-related illnesses thus leading to a slowing of the onset of the condition, prevention and, eventually, a cure.

Taking a strategic investment approach to dementia research and translation will deliver direct and indirect economic benefits to state and national economies through keeping individuals in employment for longer, minimising the need for carers to leave work, and maximising clinical outcomes at the best possible cost.

Australia is a world leader in many aspects of dementia research and treatment. Our researchers have made a number of key discoveries that have made important contributions to the body of knowledge locally and internationally.

Dementia research is now a truly international effort, with national dementia initiatives being established across the globe. The World Dementia Council Statement of Purpose (May, 2014) identified three key challenges:

- Improvements in health and care;
- Raising awareness and supporting dementia friendly communities; and
- Better research targeting a cure or modifying therapy to achieve a 5 year delay in the onset of dementia by 2025.

### 2. The role of the NNIDR

The NNIDR is one component of the Federal Government's Boosting Dementia Research Initiative which provided \$200 million over five years to Australian scientists and medical researchers working on ways to prevent, halt or

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<sup>1</sup> Australian Institute of Health and Welfare (2012) Dementia in Australia:  
<http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422943>

cure dementia<sup>2</sup>. Under the Boosting Dementia Research Initiative, the National Health and Medical Research Council (NHMRC) is delivering a series of initiatives to prioritise and fund vital new dementia research projects and translate research to improve prevention, diagnosis, treatment and care for people with dementia, their carers and communities. NHMRC National Institute for Dementia Research (NNIDR) was established to prioritise and boost dementia research in Australia and provide the focus to rapidly translate evidence into policy and practice. NHMRC engaged Alzheimer's Australia to provide the services of the NNIDR, including its establishment.

The Government's support sought to ensure that the NNIDR:

1. Dramatically expand capacity in dementia research by supporting our best new researchers to commence work on the key challenges that need to be explored;
2. Prioritise additional funding for dementia research projects in the health and aged care sector;
3. Ensure we make the most of what we already know by translating our research into better care for people with dementia; and
4. Invest in vital dementia research infrastructure to allow our scientists to develop the solutions we need.

Extensive consultation has resulted in the development of an agreed "NHMRC National Dementia Research & Translation Priority Framework"<sup>3</sup>. This Strategic Roadmap builds on the Priority Framework developed in consultation with the sector.

### **Dementia Collaborative Research Centres**

In 2006 the Federal Government, through the then Department of Health and Ageing, supported the establishment and operation of three Dementia Collaborative Research Centres (DCRCs). In 2011 responsibility for the DCRCs was transferred from the Department of Health and Ageing to NHMRC. The DCRCs have been brought together as a single program under the strategic direction of the NNIDR. This will ensure even stronger national collaboration and coordination of dementia research and translation through harnessing the capacities that the DCRCs have established a reputation for, namely:

- Dementia networks
- Knowledge translation relationships with service providers; and
- Early researcher career development opportunities

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<sup>2</sup> Coalition's Policy to boost dementia research: <http://paweb-static.s3.amazonaws.com/The%20Coalition%E2%80%99s%20Policy%20to%20Boost%20Dementia%20Research.pdf> and for further information: <https://www.nhmrc.gov.au/research/boosting-dementia-research-initiative>

<sup>3</sup> ThinkPlace "NHMRC National Dementia Research and Translation Priority Setting Framework" ([http://www.nhmrc.gov.au/files\\_nhmrc/file/research/dementia/dementia\\_phase\\_2\\_full\\_report\\_150806.pdf](http://www.nhmrc.gov.au/files_nhmrc/file/research/dementia/dementia_phase_2_full_report_150806.pdf))

## **Cognitive Decline Partnership Centre**

NHMRC established the Cognitive Decline Partnership Centre with a \$25 million commitment over 5 years commencing in 2013<sup>4</sup>. The Partnership Centre undertakes research and knowledge translation to improve the quality of care for older people with cognitive decline and their carers, including in areas such as improving aged care service planning, reducing stigma around cognitive decline, improving the size and quality of the aged care workforce, promoting responsible medication management and implementing proven models of care.

The Centre is jointly governed and supported by NHMRC and its partners: HammondCare (NSW), Helping Hand Aged Care (SA), Brightwater Care Group (WA) and Alzheimer's Australia.

## **The Opportunity**

The opportunity offered by the establishment of the NNIDR and its ability to support a national approach to dementia research and translation is unique. It provides researchers, service providers, governments and consumers<sup>5</sup> the opportunity to lay a firm foundation, one which we hope will make Australia, in the words coined somewhat poignantly at one of our planning workshops, "the best country in the world to live with dementia".

A nationally coordinated dementia research and translation effort also has the advantage of aligning and (where appropriate) integrating with other national approaches to related and co-morbid diseases such as diabetes, obesity and cardiovascular disease.

## **3. Plan Purpose**

As part of the NNIDR's leadership role in relation to dementia research and translation in Australia, the NNIDR needs to identify essential dementia research priorities for Australia across the full spectrum from basic research, to research translation and implementation. Identifying these priorities should be informed by an inventory of existing national dementia research strengths and weaknesses. The NNIDR is charged with developing a high-quality strategic roadmap for dementia research and translation priorities, measurable milestones and targets for the NNIDR.

## **4. Vision**

The NNIDR's vision is to fund and support high quality, high impact research and translation initiatives which produce genuine, positive short and long term outcomes for people living with dementia, their families, carers and the broader community.

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<sup>4</sup> Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People: <https://www.nhmrc.gov.au/grants-funding/apply-funding/partnerships-better-health/partnerships-centres/partnership-centre-deal>

<sup>5</sup> The NNIDR intends for "consumers" to include people living with dementia and their carers and families.

## 5. The NNIDR Objectives

The objectives of the NNIDR are to:

- (a) Identify essential dementia research priorities for Australia across the full spectrum from basic research to implementation;
- (b) Bring together Australia's dementia research, including existing NHMRC dementia related programs and other national initiatives, to ensure stronger coordination and collaboration;
- (c) Synthesize information provided from current research and develop strong linkages with community groups, practitioners and other service providers to rapidly and flexibly translate research outcomes;
- (d) Develop partnerships between researchers, industry and philanthropic organisations to help embed dementia research into the health system and stimulate the translation and implementation of research findings into policy and practice; and
- (e) Ensure Australian participation in major international collaborations relevant to dementia research.

The NNIDR is working with Alzheimer's Australia to involve consumers in every stage of dementia research to ensure consumer driven research and translation priorities and outcomes. The NNIDR is developing an innovative, research strategy by working with consumers and researchers to ensure that international best practice in consumer involvement in research is adopted and implemented in all of its activities.

## 6. NHMRC National Dementia Research & Translation Priority Framework

Extensive national consultation established five priorities and twelve desired outcomes. The agreed priorities, which are presented not as a hierarchy but as a logical sequence, include:

### 1. Prevention

#### *Outcomes*

- There is an increased understanding of the Australian population's risk factors and how they change over a lifespan
- There are effective interventions to reduce the risk of dementia and lower the incidence of dementia

### 2. Assessment and diagnosis

#### *Outcomes*

- Diagnosis is coordinated and supported
- The accuracy and timeliness of assessment and diagnosis are continuously improving

### 3. Intervention and treatment

#### *Outcomes*

- New understanding informs approaches to treatment

- There are effective interventions to sustain independence and improve quality of life and quality of care
  - There are new, innovative treatments to delay or prevent dementia progression
4. Living with dementia
- Outcomes*
- There is increased awareness and understanding of rights, needs and experience of people with dementia living in the community
  - The dignity, independence and self-determination of people with dementia are supported
5. Care
- Outcomes*
- High quality clinical care that improves quality of life is provided for people with dementia and their carers in all environments
  - A multidisciplinary approach to individualised care improves quality of care and quality of life
  - Consumer choice drives improvement to quality of care

## 7. Governance

The NHMRC National Institute for Dementia Research (NNIDR) was established to prioritise and boost dementia research in Australia and provide the focus to rapidly translate evidence into policy and practice. NHMRC has engaged Alzheimer’s Australia to provide the services to NHMRC for the NNIDR. NHMRC is the overarching funding body with responsibility for funding dementia research.

Governance and coordination of the NNIDR is summarised in the Principles, processes and diagram that follows.

### *Principles*

Six principles guide governance for the NNIDR.

#### **1. Aligned research priorities**

The NNIDR’s task is to coordinate and strategically align research priorities and performance in dementia across Australia across sectors, fields and geography.

#### **2. Partnerships**

Powerful partnerships between all stakeholders provide leadership and a diversity of perspectives to design coordinated programs of research in complex multidisciplinary environments. The aim is to optimise cross-disciplinary and cross-sector innovation and to enable research in complex environments.

#### **3. Continuity**

The NNIDR will work to ensure that infrastructure and processes are established to enable sustainable coordination and sharing of resources and data between dementia researchers in partnership with service providers and consumers. The Institute will support research programs that incorporate continuity and cycles of learning and engagement.

#### **4. Translation**

Translation is defined as the principle of turning discoveries and knowledge into improvements in human health and economic benefit with the aim of driving innovation, speeding up the transfer of the best ideas into new interventions and improving the returns on research investment

#### **5. Novelty**

The Institute itself is a novel model of coordinating research and translation in Australia. The NNIDR seeks new, innovative models for research, novel research ideas, and accelerated translation.

#### **6. Legacy**

The Institute aims to support research that can be sustained beyond the life of the current “Boosting Dementia Research Initiative” and provide evidence to governments and other funders of the value in continuing to fund dementia research into the future.

### *Consumer Involvement*

The NNIDR seeks to develop strong consumer involvement as an underpinning base of each of its governance principles. Consumer involvement in research is defined as an active partnership between consumers and researchers should include involvement in priority setting, knowledge generation and knowledge transfer, such that projects are done ‘with’ consumers rather than ‘to’, ‘about’ or ‘for’ consumers.

### *High level governance processes*

Alzheimer’s Australia operates the NNIDR within the remit and broader governance arrangement of NHMRC, with NHMRC retaining final approval of key NNIDR deliverables. The NNIDR is led by the NNIDR Director, who is responsible for delivering the key objectives of the NNIDR. The Director in turn is advised by an Expert Advisory Panel made up of experts in all aspects of dementia including researchers, clinicians, policy makers, service providers and consumers.

The Expert Advisory Panel (EAP) provides advice to the NNIDR Director. The EAP comprises key multidisciplinary and multi sector stakeholders to guide the NNIDR’s priorities. The EAP has a critical role to provide dementia research expertise to the NNIDR to guide implementation of initiatives.

The role of the NNIDR Board is to assist Alzheimer’s Australia to oversee the delivery of services for the NNIDR and supervise the NNIDR Director’s performance.

### *The Strategic Roadmap*

This strategic roadmap should be used to drive coordination and facilitate collaboration across dementia research and translation initiatives across Australia. The NNIDR will review the Strategic Roadmap annually, including consulting stakeholders, to track research outcomes and progress against milestones and targets and consider gaps and priorities for NHMRC for the year ahead. NHMRC CEO will consider relevant priorities from the Strategic Roadmap in developing NHMRC’s corporate plan.

## 8. Overview of key NNIDR programs

Major programs operating under the NNIDR umbrella are summarised below.

### *a) NHMRC Dementia Research Team Grants (DRTG)*

Dementia Research Team Grants provide support for teams of researchers over five years to pursue collaborative research, promote effective translation of research, and develop capacity. Funding supports dementia research across a variety of areas including:

- Discovery Research;
- Clinical Research;
- Population Health Research; and
- Health Services Research

Six Dementia Team Grants have been funded with a commitment of \$35.5M over 5 years.

### *b) NHMRC-ARC Dementia Research Development Fellowships*

NHMRC- ARC Dementia Research Development Fellowship scheme provides support for postdoctoral researchers to undertake advanced research training in fields relevant to dementia such as health, medical, fundamental sciences, social, economic and cultural studies, either in Australia or overseas. For PhD researchers, the scheme has targeted those within four years of having gained their postgraduate degree, however, for clinician researchers there is no equivalent limit, thus achieving an important goal of boosting clinician researchers. It is a bold initiative to boost the dementia research workforce in order to support increased research activity. There were 76 Fellows funded in this program across Australia.

### *c) Boosting Dementia Research Leadership Fellowships*

The aim of the Boosting Dementia Research Leadership Fellowships Scheme is to maintain and expand research leadership by ensuring mid-tier researchers with international standing are recruited and/or retained within Australian dementia research teams of demonstrated excellence and international standing. Successful Fellows will have a sustained track record of significant, peer-reviewed, quality research outputs as judged relative to opportunity, and will be required to participate in NNIDR activities.

### *d) Clem Jones Centre for Ageing Dementia Research (CJCADR)*

The Clem Jones Centre for Ageing Dementia Research is based at the Queensland Brain Institute of the University of Queensland. The Centre has received \$9 million over four years for research into the prevention and treatment of dementia, in accordance with the Australian Government's election commitment. The Centre comprises a number of laboratories with complementary expertise aimed at assisting in the development of therapies, tests and tools that will help to prevent and treat dementia in the Australian population and internationally.

The research objectives of the Centre are to:

- understand at an integrated level the cellular and biochemical changes that the brain undergoes in healthy and pathological ageing, and hence understand the mechanisms involved;
- develop new technologies and tools to better understand pathological processes;
- develop better diagnostic tools, methods and biomarkers; and
- develop new treatments and methods of prevention.

The Centre undertakes its activities in close liaison with the NNIDR.

#### *e) Multinational collaborative projects: JPND*

On NNIDR advice, NHMRC has allocated funding to support a small number of Australian-based researchers who are participating as external collaborators on international consortia under the European Union Joint Program – Neurodegenerative Disease (JPND). NHMRC National Institute for Dementia Research provides merit-based funding, where the transnational consortium has been favourably reviewed by the JPND, for the Australian-based components of this research with a focus on “Alzheimer’s disease and other dementias”. Two grants have been supported under the JPco-fuND program 2015 call (risk and protective factors, longitudinal cohort approaches and advanced experimental models) and grants are currently being considered for funding in 2017 (pathway analysis across neurodegenerative diseases).

#### *f) Implementation of Dementia Research Into Clinical Practice and Care*

The aim of this initiative is to improve the lives of people with dementia and their carers through improving clinical practice and increasing the quality of care; support the identification of effective ways of ensuring that dementia care research is implemented in various settings, such as hospitals, community, aged care facilities and general practice; and to support the translation of one or more Clinical Practice Guidelines and Principles of Care for People with Dementia in Australia.

#### *g) Dementia in Indigenous Australians*

On NNIDR advice, NHMRC has made a Targeted Call for Research into Dementia in Indigenous Australians. The Scheme will support culturally appropriate research specifically addressing the health and care needs of Aboriginal and Torres Strait Islanders living with dementia and the impact on their families and carers.

Applications must demonstrate shared ownership between Indigenous Australians, their communities, Indigenous health service providers and researchers.

#### *h) Dementia Collaborative Research Centre Network (DCRCs)*

The Mission of the DCRCs is: "Translating Dementia Research into Practice"

There are three DCRCs:

- *Assessment and Care*  
Located at University of New South Wales (UNSW) and focussed on issues of assessment of dementia and improving care
- *Carers and Consumers*  
Located at Queensland University of Technology (QUT) and focussed on quality of life and care for people with dementia and carers
- *Early Diagnosis and Prevention*  
Located at the Australian National University (ANU) and focussed on early detection and diagnosis of dementia as well as risk reduction and prevention of dementia

The three Dementia Collaborative Research Centres are transitioning to operate as a single, unitary program under the strategic direction of the NNIDR although they remain structurally independent within their host institutions. The DCRCs conduct commissioned research and may be conceived as providing the internal research program of the NNIDR.

In addition, the DCRCs have worked closely with the former Consumer Dementia Research Network, the National Dementia Quality Care Network and other dementia programs, including DTSCs (now DTA).

#### *i) Cognitive Decline Partnership Centre (CDPC)*

NHMRC Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People (Cognitive Decline Partnership Centre) situated at the University of Sydney, aims to improve the lives of people with dementia by developing, communicating, and implementing research that improves care. Its approach is guided by a commitment to working together, diversity, and translating rigorous research into practice. The Centre brings together consumers, industry partners, researchers and clinicians to develop relevant research questions and ensure findings are applicable to the current care environment for people with dementia.

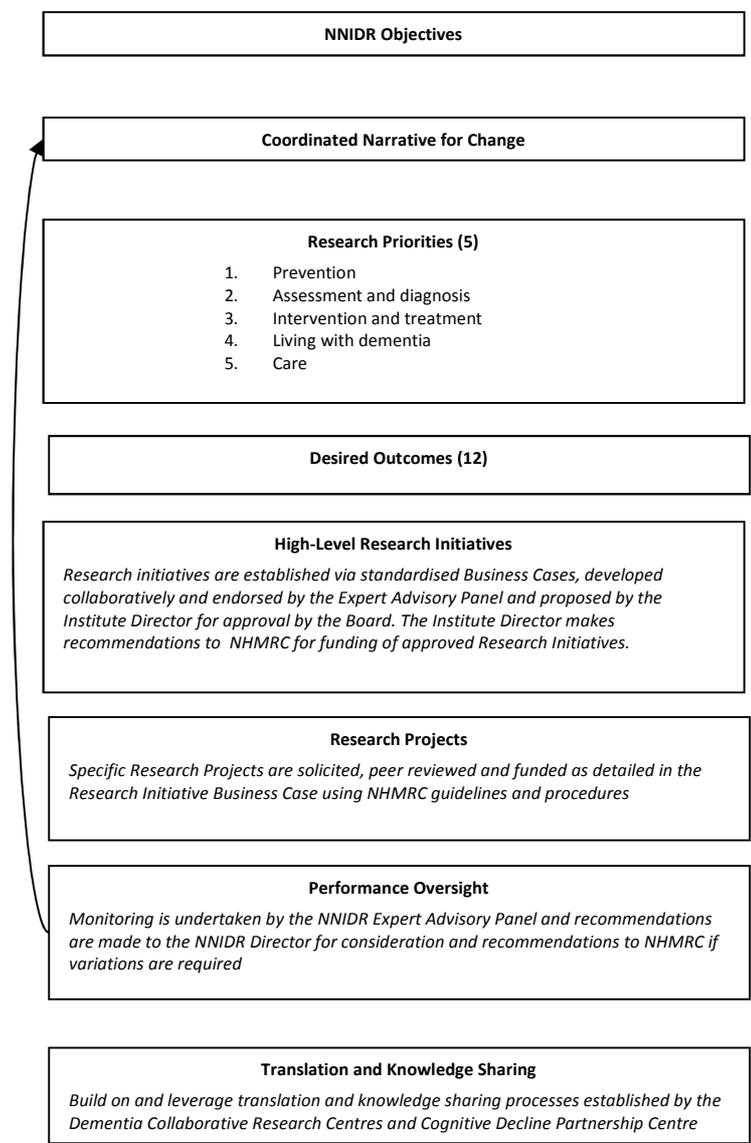
The Centre's research foci includes:

- Development of the first Clinical Practice Guidelines for Dementia in Australia.
- Advance care planning: how it is different for people with dementia.
- Embedding the care of the Confused Hospitalised Older Person (CHOPs) program across hospitals in NSW and beyond.

*j) Additional NNIDR programs*

In addition to the programs listed above the NNIDR, through the Director, also recommends new programs of research to NHMRC based on business cases reviewed and endorsed by the Expert Advisory Panel. The purpose of these programs is develop a dynamic and focussed body of high quality, integrated portfolio of research that fills agreed gaps in knowledge and across the NNIDR’s objectives, priorities and outcomes.

The diagram below outlines the implementation framework for this aspect of the NNIDR’s work. Although the diagram emphasises a linear flow from top to bottom, actual interactions, driven by our guiding principles and the collegial nature of the research activities, will ensure dynamic and innovative exchanges.



## 9. Program Evaluation and Review

Progress towards delivering the NNIDR Strategic Roadmap for Dementia Research will be reviewed annually by the Expert Advisory Panel and Board. Performance by research teams in achieving specified outcomes will be routinely monitored with a view to ensuring value for money is achieved from the Government's significant investment in boosting dementia research.

The Boosting Dementia Research Initiative as a whole will be evaluated in 2018 – 2019.

## 10. Other relevant non-NNIDR dementia research programs

Other dementia programs that are a critical part of the research landscape are included here for context. These are not part of the NNIDR, however they do include potential collaborators, stakeholders and members of the Institute.

### *k) Dementia training for the aged care sector<sup>6</sup>*

On 1 October 2016, Dementia Training Australia (DTA) became the national provider of the Dementia Training Program, replacing the Dementia Training Study Centres (DTSCs) which had been established by the Australian Government in 2006. The DTA program<sup>7</sup> offers accredited education, upskilling, and professional development for the workforce providing dementia care in the primary, acute and aged care sectors.

DTA provides:

- Continuing Professional Development training on dementia assessment, diagnosis and management to GPs, nurses, pharmacists, psychologists, specialists, allied health and other relevant professionals as appropriate
- Accredited dementia care vocational level training courses – free to eligible care workers in residential, respite, community care or the wider health services and
- Tailored onsite training to aged care providers who request assistance, including a dementia skills and environment audit, followed by a tailored training package.

DTA has strong linkages to dementia research organisations and consumer groups. This ensures ongoing commitment to timely knowledge translation – with training activities and resources reflecting contemporary best evidence in dementia care, and informed by the needs and preferences of persons living with dementia and their families.

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<sup>6</sup> This section has been updated with information provided by the Department of Health (Feb 2017) to reflect the transition from DTSC to DTA.

<sup>7</sup> [www.dementiatrainingaustralia.com.au](http://www.dementiatrainingaustralia.com.au)

### *l) Dementia Support Services<sup>8</sup>*

The Dementia Behaviour Management Advisory Services (DBMAS) is a national service funded by the Department of Health. DBMAS provides locally based individualised support for the carers of people living with dementia whose behavioural and psychological needs are impacting on the person's care and quality of life.

On 1 October 2016, Dementia Support Australia (DSA) became the national provider of the Dementia Behaviour Management Advisory Service (DBMAS)<sup>9</sup>.

DBMAS services are free of charge and include:

- Assessment of the person living with dementia
- Clinical support, information and advice (face to face and via telephone or email)
- Care planning, case conferences and short term case management
- Mentoring and clinical supervision
- Capacity and knowledge building for care providers.

Where a person in residential aged care is experiencing severe and extreme behavioural and psychological symptoms, DBMAS can refer them to the Severe Behaviour Response Teams (SBRTs) for more specialised support. The SBRTs are also delivered by DSA.

### *m) NHMRC funded dementia research*

NHMRC funds dementia research through its existing grant schemes and fellowships, separate from those schemes within the NNIDR. NHMRC funding schemes remain open to dementia researchers throughout the Boosting Dementia Research Initiative.

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<sup>8</sup> This section has been updated with information provided by the Department of Health (Feb 2017).

<sup>9</sup> [www.dementia.com.au](http://www.dementia.com.au)