AUSTRALIA’S
BOOSTING DEMENTIA
RESEARCH INITIATIVE
Report on early outcomes

Accelerating research. Enhancing collaboration. Creating change.
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Dementia is one of the world’s greatest health challenges. Without a medical breakthrough, it is predicted that more than 1.1 million Australians will be living with dementia by 2056.

The Turnbull Government is focused on delivering ground breaking new medical research to Australians. Through the National Health and Medical Research Council (NHMRC), the Medical Research Future Fund and the Biomedical Translation Fund, the Australian Government is delivering more than $6 billion to support Australian patients and researchers, and improve research translation over five years from 2016–17.

A long-term approach to the diagnosis and treatment of dementia—informing targeted, collaborative research—is essential for Australia’s social and economic wellbeing, and on an individual basis to help people reduce risk and delay progression of dementia and to improve quality of life for people living with dementia.

The Australian Government’s Boosting Dementia Research Initiative is providing $200 million over five years to accelerate research, enhance collaboration and create change in dementia research and treatment. The NHMRC National Institute for Dementia Research (NNIDR) was established in July 2015 to coordinate this work, and support effective translation of research results into positive outcomes for people living with dementia, their families, carers and the broader community. This is a strategic investment in high quality, high impact research.

Australia is a world leader in many aspects of dementia research and treatment. Our researchers have made key discoveries and important contributions to the body of knowledge locally and internationally. The Boosting Dementia Research Initiative is bringing the best researchers together, across Australia and internationally, to share knowledge and coordinate research efforts.

Since the Initiative was announced in 2014, a total of 127 grants have been awarded to 285 leading dementia researchers working across 24 universities and research institutions. Funded research ranges from two to four years duration, with early outcomes already showing promise and an increase in dementia-related outputs.

Key successes already include studies into ultrasound technology, which is offering the potential for a new, non-invasive way to improve memory and slow cognitive decline, while other researchers are discovering more about the impact of childhood stress as a risk factor, particularly among Indigenous Australians, and trials are underway to explore if eye scans can reveal early signs of cognitive decline.

I am pleased to see the promising early outcomes and progress made possible through the Boosting Dementia Research Initiative.

The Honourable Greg Hunt MP
Minister for Health
The NNIDR is a key element of the Australian Government’s $200 million initiative to boost dementia research.

Established on 1 July 2015, the NNIDR is targeting, coordinating and translating the strategic expansion of dementia research in Australia.

This includes collaborating with Australia’s best researchers while also drawing on the expertise of consumers, health professionals, industry and policy makers to set national research priorities and translate evidence into policy and practice.

The NNIDR is delivered by Dementia Australia—Australia’s peak body representing people living with dementia. The NNIDR sits within the NHMRC, developing dementia research strategy on the advice of the NNIDR Board and Expert Advisory Panel, and ensuring the outcomes from this significant investment address identified community needs.

In this way, the NNIDR is making a significant contribution to the World Dementia Council’s international priority of achieving a five-year delay in the onset of dementia by 2025.

This is the NNIDR’s first public report on research projects funded under the Boosting Dementia Research Initiative.

It explains the five research priority areas—prevention, assessment and diagnosis, intervention and treatment, living with dementia, and care—including why they are important and the desired outcomes for each area.

The report also profiles examples of funded research projects across these five areas. With more than 100 large-scale, multi-year projects now underway, these case studies just touch the surface of the many and varied ways funded research is improving understanding about dementia and making inroads into reducing its prevalence and impact, today and into the future.

Janice Besch
Director, NNIDR
DEMENTIA IN AUSTRALIA

One of Australia’s greatest health challenges

MORE THAN 425,000 AUSTRALIANS ARE LIVING WITH DEMENTIA

+244 PEOPLE JOIN THIS NUMBER EVERY DAY (approx 1700 per week)

APPROXIMATELY 1.2 MILLION AUSTRALIANS involved in care for people with dementia

DEMENTIA COSTS ARE EXPECTED TO REACH $15 BILLION IN 2018, AND OUTSTRIP SPENDING ON ANY OTHER HEALTH CONDITION BY THE 2060s

MOST FEARED CONDITION for Australians over the age of 60

SECOND LEADING CAUSE of death in Australia

Research can change this...

$200 MILLION Boosting Dementia Research Initiative

$150 MILLION to scale up dementia research to help improve prevention and find treatments and cures

$50 MILLION to prioritise and coordinate the national research effort, and integrate with international efforts, to ensure new and existing research translates into better care for people with dementia

127 research grants awarded for fellowships, projects and collaborative research as at 31 December 2017

5 PRIORITY RESEARCH AREAS

PREVENTION

ASSESSMENT AND DIAGNOSIS

INTERVENTION AND TREATMENT

LIVING WITH DEMENTIA

CARE
**ACTIONS TO BOOST DEMENTIA RESEARCH**

### 2014
- $200 million allocated to the Boosting Dementia Research Initiative through the 2014–15 Federal Budget
- Stakeholder consultations on research priorities commenced
- Funding call for four-year early career fellowships
- Funding call for large-scale collaborative research projects in priority areas
- Commonwealth funding ($9 million) for the Clem Jones Centre for Ageing Dementia Research commenced

### 2015
- The NNIDR established
- 76 Development Fellowships ($43.7 million) awarded to early career researchers across all priority areas
- Six Dementia Research Team Grants ($35.6 million) awarded
- Australia joins the European Union Joint Program for Neurodegenerative Disease (JPco-fuND)

### 2016
- $2.6 million awarded to two Australian researchers participating in JPco-fuND: European research projects
- Coordination and Collaboration Framework established, setting expectations for the NNIDR in fostering a cohesive research effort
- The NNIDR Membership Network founded as a national platform for collaboration and coordination in dementia research

### 2017
- Call for Multinational Research Projects for Pathway Analysis Across Neurodegenerative Diseases issued jointly with European Union counties
- The NNIDR National Public Lecture Tour held
- Targeted Call for Research into Dementia in Indigenous Australians issued

### 2018
- International Research Network on Dementia Prevention officially launched
- 32 Boosting Dementia Research Leadership Fellowships ($22.6 million) awarded
- 13 Boosting Dementia Research Grants ($17.6 million) awarded to implement research into clinical care and practice

### 2019
- Call for a National Dementia Network issued
- Second Australian Dementia Forum [ADF2018], Progress on the Boosting Dementia Research Initiative, held in Melbourne
- Australia enters fourth European collaboration

- Report on early outcomes of boosting Dementia Research Initiative released
BOOSTING RESEARCH TO CREATE CHANGE

Dementia is a significant health issue. Improving prevention, treatment and care is an Australian, and global, priority.
MORE AUSTRALIANS ARE BEING DIAGNOSED WITH DEMENTIA

As we live longer and our population ages, the number of Australians with dementia is increasing.

More than 400,000 people are estimated to be living with dementia in Australia today and, with more than 240 new cases each day, the number is expected to exceed 1.1 million by 2056. (2 p.54)

Dementia is a disorder characterised by impairment in memory, thinking and behaviour resulting in an inability to perform everyday activities. It is usually progressive over time and can be caused by over 100 different conditions of which Alzheimer’s disease is the most common. Other common forms include vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia is a significant health issue. It is the greatest cause of disability in Australians aged 65 years and older (3 p.85), and Australia’s second leading cause of death. (1)

While dementia is more common after the age of 65, it is not a normal part of ageing and younger people can also have dementia. More than 25,000 people under the age of 65 are estimated to be living with younger onset dementia, and this is expected to rise to more than 40,000 by 2056. (2 p.6)

Worldwide, more than 46.8 million people live with dementia. (5 p.60) Improving prevention, treatment and care is an Australian, and global, priority. (5 p.51)

A $200 MILLION RESEARCH BOOST

In 2014 the Australian Government announced an additional $200 million in funding for Australian scientists and medical researchers working on ways to prevent, treat or cure dementia. This five-year Boosting Dementia Research Initiative includes:

- $150 million to urgently scale up dementia research through:
  - $95 million for large-scale research projects in priority areas of dementia
  - $46 million to dramatically expand research capacity in dementia and build the future research workforce
  - $9 million for research focused on prevention and treatment at the Clem Jones Centre for Ageing Dementia Research.

- $50 million to target, coordinate and translate the national research effort into better care for people with dementia, through the NNIDR.

A DRIVE TO IMPROVE OUTCOMES

We need better care now for the people living with dementia, while we look for a cure.

Australia is a world leader in many aspects of dementia research and treatment. We have a unique opportunity to leverage our research strengths, and enhance collaboration both within Australia and internationally, to deliver real time, real world outcomes. This includes ways to improve diagnosis, care, awareness and support, as researchers continue working on how to prevent and, ultimately, cure dementia.

‘Scientific output related to dementia has increased significantly since 2016. Indeed, Australian dementia related outputs are expanding at double the rate of growth globally and significantly faster than Australian output in other domains.’

Thomas Barlow
NNIDR: Dementia Bibliometric Report 2017
[internal report commissioned by the NNIDR]
THE NNIDR: COORDINATING RESEARCH EFFORTS
The NNIDR is a key part of Australia’s Boosting Dementia Research Initiative. It has been established to target, coordinate and translate the strategic expansion of dementia research in Australia, and connect to consumers.

The NNIDR identifies Australian priorities for dementia research and links new and existing research for stronger coordination and collaboration.

To translate research results into policy and practice, the NNIDR works with Australia’s best researchers, supports international partnerships, and draws on the expertise of consumers (people living with dementia and their carers), health professionals, industry and policy makers.

The vision is to support high quality, high impact research and initiatives that translate into positive outcomes for people living with dementia, their families, carers and the broader community.

Creating a community of researchers
The NNIDR has recruited around 400 members, both individuals and organisations. Members include researchers funded under the Boosting Dementia Research Initiative and broader stakeholders in dementia research.

Involving consumers
Strong consumer involvement is important to ensure research is conducted in active partnership with those affected by dementia, so they have a say in setting research priorities, and generating and transferring knowledge.

SETTING NATIONAL PRIORITIES
The NNIDR’s Strategic Roadmap for Dementia Research and Translation guides national priorities for dementia research and translating the research effort into better care for people with dementia.

The Roadmap articulates the NNIDR’s vision, objectives, principles and priorities. It underpins the NNIDR’s activities and provides the structure to enhance collaboration and coordination in Australian dementia research.

The Roadmap also guides reporting on research priorities and funding recommendations under the Boosting Dementia Research Initiative and other relevant NHMRC programs. The Strategic Roadmap is updated regularly and is available at www.nnidr.gov.au.

Working to guiding principles
Six principles guide the NNIDR’s work:

- **Aligned research priorities.** The NNIDR coordinates and strategically aligns priorities and performance in dementia around Australia, across sectors, fields and geography.

- **Partnerships.** Powerful partnerships between all stakeholders provide leadership and diverse perspectives to design coordinated research programs. The aim is to optimise innovation across sectors and disciplines, and enable research in complex environments.

- **Continuity.** The NNIDR helps establish infrastructure and processes that enable sustainable coordination and sharing of resources and data between dementia researchers, in partnership with service providers and consumers. The NNIDR supports research programs that incorporate continuity and cycles of learning and engagement.

- **Translation.** Translation means turning discoveries and knowledge into improvements in human health and economic benefit. The aim is to drive innovation, speed up the transfer of the best ideas into new interventions and improve returns on research investment.

- **Novelty.** The NNIDR is a novel model of coordinating research and translation in Australia. It seeks new, innovative models for research, novel research ideas and faster translation.

- **Legacy.** The NNIDR supports research that can be sustained beyond the life of the Boosting Dementia Research Initiative, and provides evidence to governments and other funders of the value of continuing to fund dementia research into the future.

MAJOR RESEARCH PROGRAMS
Boosting Dementia Research Initiative programs
Research in priority areas is happening through the following major programs delivered by the NHMRC, with strategic oversight from the NNIDR.

Key programs are:

- **Clem Jones Centre for Ageing Dementia Research.** This Centre is based at the Queensland Brain Institute of the University of Queensland. With specialist laboratories and expertise, the Centre focuses on assisting the development of therapies, tests and tools to help prevent and treat dementia. The Centre has received $9 million in funding, matched by a further $9 million from the Queensland Government.

- **Dementia Research Team Grants.** These grants support teams to pursue collaborative research, promote effective translation of research and develop capacity.
• **NHMRC-ARC Dementia Research Development Fellowships.** This joint NHMRC and Australian Research Council (ARC) scheme aims to boost the workforce by linking new researchers, who have been awarded PhDs in the last four years, with dementia research teams. The intention is to broaden the skills base and deepen the available pool of talented researchers to facilitate more innovative and intensive research on dementia.

• **Boosting Dementia Research Leadership Fellowships.** This scheme follows the early career fellowships, and aims to maintain and expand leadership in dementia research by supporting mid-career researchers to transition to leadership positions. This ensures that Australian dementia research teams with demonstrated excellence and international standing recruit or retain mid-tier researchers who are also internationally recognised.

• **Multinational collaborative projects—European Union Joint Programme—Neurodegenerative Disease Research.** A small number of Australian-based researchers are participating as external collaborators on international consortia under this Joint Programme. They are focusing on Alzheimer’s disease and other dementias.

• **Implementation of Dementia Research into Clinical Practice and Care.** This initiative aims to improve the lives of people with dementia and their carers by improving clinical practices and increasing the quality of care—supporting implementation of dementia care research across hospitals, aged care facilities, in general practice and in the community.

• **Research into Dementia in Indigenous Australians.** This Targeted Call will support culturally appropriate research, specifically addressing the health and care needs of Aboriginal and Torres Strait Islander people living with dementia, and the impact on their families.

• **National Dementia Network.** This program will support a clinical quality registry that will monitor the appropriateness and effectiveness of dementia healthcare by routinely collecting, analysing and reporting health-related information. The registry will also be helpful to identify smaller groups based on certain characteristics, for participation in clinical trials.

The NNIDR also recommends new programs of research to government in addition to those listed above, to help fill gaps in knowledge across the agreed research priority areas. The NNIDR’s Expert Advisory Panel and Board provide advice on priorities and closely monitor programs to ensure outcomes are delivered in accordance with the Strategic Roadmap.

**Other related programs**

Several other relevant programs link to the work of the NNIDR, and involve a broad range of collaborators, stakeholders and Institute members. These include:

• **Dementia Centre for Research Collaboration.** The Centre’s mission of ‘translating dementia research into practice’ is delivered through three flagship research projects, and capacity building and knowledge translation programs, hosted by the University of New South Wales and Queensland University of Technology. The three flagship research projects are coming together to operate as a single program under the NNIDR’s strategic direction.

• **NHMRC Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People (Cognitive Decline Partnership Centre).** This Centre at the University of Sydney aims to improve the lives of people with dementia by developing, communicating and implementing research that improves care. The centre brings together consumers, industry partners, researchers and clinicians to develop relevant research questions and ensure findings can be applied to the current care environment for people with dementia.

• **Dementia Training Australia.** This consortium develops and assures a national approach to accredited education including upskilling and professional development for the workforce providing dementia care in the primary, acute and aged care sectors.

• **Dementia Behaviour Management Advisory Service.** Funded by the Australian Department of Health, this service provides locally based support for carers of people living with dementia, whose behavioural and psychological needs are affecting their care and quality of life.

• **NHMRC-funded dementia research.** Other existing NHMRC grant schemes and fellowships remain open to dementia researchers. Funding is monitored to ensure projects in the dementia research effort are coordinated and complementary.
NON-INVASIVE ULTRASOUND MAY HELP TREAT DEMENTIA

‘This work opens up an entirely novel avenue for future therapeutic treatment.’

PROFESSOR JÜRGEN GÖTZ
DIRECTOR, CLEM JONES CENTRE FOR AGEING DEMENTIA RESEARCH
NON-INVASIVE TECHNIQUE

Studies have shown that using ultrasound technology can enhance the effectiveness of an antibody fragment drug, enabling the brain to clear toxic protein aggregates that impact cognitive function.

Scientists at the Clem Jones Centre for Ageing Dementia Research, based within the Queensland Brain Institute, believe this non-invasive therapy could be used to slow cognitive decline, restore memory, and treat Alzheimer’s disease.

In Alzheimer’s disease, two toxic proteins, known as β-Amyloid and tau, build up within the brain, damaging nerve cells and impacting memory.

The 2017 Clem Jones Centre study (7) shows that using scanning ultrasound, together with an antibody fragment drug to reduce symptoms, allows for more medication to get into the brain to clear out the toxic tau protein build-up that (together with β-Amyloid) causes Alzheimer’s.

Reducing those toxins leads to an improvement in cognitive function in trials on mice and, with further research, the scientists are confident results could lead to a new therapeutic approach that provides similar results for people with dementia.

Using the ultrasound temporarily and safely opens the ‘blood-brain barrier’. The barrier is there to protect the brain but can be a hindrance to science, particularly for those trying to treat brain diseases. It is also an obstacle to many drugs developed for brain diseases.

BACKGROUND

More than 400,000 Australians live with dementia and, of these, it is estimated that between 50 and 75 per cent have Alzheimer’s disease, which is the most common form of dementia. (6 p.2)

In 2015, the team at the Clem Jones Centre first trialled the ultrasound technique on genetically engineered mice with an amyloid pathology. They found it not only cleared β-Amyloid but also restored memory function to the same level as healthy mice.

The new study in 2017, which also used the antibody fragment drug, illustrates the potential of the ultrasound technology in effectively delivering therapeutic agents to the brain.

IS THIS TECHNIQUE VIABLE?

Human clinical trials are still several years away. However, scientists believe the new technique has considerable promise. Professor Jürgen Götz, Director of the Clem Jones Centre, says the combination treatment has the potential to increase uptake of the therapeutic antibody fragment into the brain, and could be used to make treatments for brain diseases more cost-effective.

In dementia vaccination trials elsewhere, the problem is that only 0.1 per cent of the therapeutic antibodies enter the brain. Antibody therapies could cost an estimated $25,000 to $100,000 per person per year. (7 p.470) This recent research could drastically reduce the cost of these treatments.

The Clem Jones Centre team is doing ongoing work to translate the research into a safe therapy for people with Alzheimer’s disease in coming years.

POTENTIAL BEYOND ALZHEIMER’S DISEASE

Scientists at the Clem Jones Centre also believe the successful outcome in the lab of using ultrasound technology to clear toxic protein build-up from the brain gives hope for new treatments for a range of dementias and other brain-related illnesses, including multiple sclerosis, Huntington’s and motor neuron disease.
RESEARCH PRIORITY AREAS

Funded research ranges from laboratory work to studies involving people with dementia and health care staff. All funded research focuses on one or more of the identified priority areas of prevention, assessment and diagnosis, intervention and treatment, living with dementia, and care.
FIVE RESEARCH PRIORITY AREAS

Funded research focuses on these priorities identified in the NNIDR’s Strategic Roadmap:

- prevention
- assessment and diagnosis
- intervention and treatment
- living with dementia
- care.

Each priority area has specified desired outcomes.

While funded projects are categorised under one main research priority area, these areas represent a continuum, with many projects relevant across more than one aspect of the Strategic Roadmap.

RANGE OF FUNDED RESEARCH

As at 31 December 2017, approximately $130 million has been allocated to 127 research grants, spanning the disciplines of clinical medicine and science, basic science, health services, and public health.

A total of 285 researchers across 24 universities and research institutions are involved.

The research ranges from two to four years’ duration, with the first grants finishing in 2018 and the last finishing in 2021.

Investment in fellowships includes both early career and leadership roles.

Funding for 76 successful Development Fellowship applications commenced in 2016, with over $43 million committed.

These fellowships are providing opportunities for postdoctoral researchers to undertake advanced training in the health, medical, fundamental sciences, social, economic and cultural fields relevant to dementia, in Australia or overseas.

In addition, 32 Leadership Fellows have now been funded across Australia, with $22.6 million committed.

A total of $53.2 million has been allocated to 19 large-scale projects, and $3.5 million has been allocated to three international collaboration grants.

‘Australian institutions that have received new dementia funding through the NHMRC account for most of the dementia-related research in Australia, as well as for much…of the recent increases in output.’

Thomas Barlow

*NNIDR: Dementia Bibliometric Report 2017 [internal report commissioned by the NNIDR]*
ABOUT THE NNIDR

MISSION
To target, coordinate and translate the strategic expansion of dementia research in Australia.

VISION
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.

OBJECTIVES
• Identify essential dementia research priorities for Australia across the full spectrum from basic research to implementation.
• Bring together Australia’s dementia research, including existing NHMRC dementia related programs and other national initiatives, to ensure stronger coordination and collaboration.
• 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.
• 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.
• Ensure Australian participation in major international collaborations relevant to dementia research.

PUTTING PEOPLE FIRST IN RESEARCH
The NNIDR is working with Dementia Australia to involve members of the public who have experienced dementia in their lives in every stage of dementia research to achieve better research and translation priorities and outcomes. The NNIDR aims for international best practice in public involvement in research across all its activities.

DESIRED RESEARCH OUTCOMES
Prevention:
• increased understanding of the Australian population’s risk factors and how they change over a lifespan
• effective interventions to reduce the risk and lower the incidence of dementia.

Assessment and diagnosis:
• coordinated and supported diagnosis
• effective interventions to reduce the risk and lower the incidence of dementia.

Intervention and treatment:
• new understanding informs approaches to treatment
• effective interventions sustain independence and improve quality of life and quality of care
• new innovative treatments delay or prevent dementia progression.

Living with dementia:
• increased awareness and understanding of the rights, needs and experiences of people with dementia living in the community
• support for their dignity, independence and self-determination.

Care:
• improved quality of life and care for people with dementia and their carers through high quality clinical care in all environments
• a multidisciplinary approach to individualised care
• consumer choice to drive improvements.
PREVENTION RESEARCH

WHY PREVENTION RESEARCH IS IMPORTANT

The lifestyle risk and protective factors for dementia offer important opportunities for prevention programs to reduce the number of Australians developing dementia each year.

Internationally, the World Health Organization recently listed evidence-based practice for dementia risk reduction as one of its seven cross-cutting principles informing its global action plan to reduce the global burden of dementia. (9 p.5)

However, while there is good evidence that we can reduce the risk of dementia by changing lifestyle and behaviour, we need to further develop the evidence base and better understand the interaction between lifestyle and genetic factors.

For example, we know that the incidence of dementia decreases across generations with strategies to reduce risk to prevent or delay the onset of the condition. However, we do not yet know exactly how these risk factors contribute to cognitive health, or what specific measures or treatments provide the best protection. (10, 11)

Many of the known risk factors for dementia are the same as for non-communicable, lifestyle-related diseases including cancer, diabetes and hypertension. Strategies to reduce these risks, such as not smoking, having a healthy diet and exercising, are also good for brain health and for reducing the risk of cognitive decline and dementia.

Desired outcomes of prevention research

The desired outcomes for research in the priority area of prevention are:

- increased understanding of the Australian population’s risk factors and how they change over a lifespan
- effective interventions to reduce the risk and lower the incidence of dementia.

Funded prevention research

There are 24 funded activities focusing on prevention. This includes 21 fellowship grants and three large-scale projects across 13 universities and research institutions.

Examples of this research include:

- analysing data of prescription sequences to understand which drugs may impair cognition
- studying whether public access to green spaces can help reduce the risk of Alzheimer’s over the long-term by improving mental health and cognition
- examining the ways vascular burden may contribute to dementia
- developing effective, culturally appropriate, and accessible strategies to promote healthy brain ageing and prevent dementia in Indigenous communities
- looking for shared gene variants that cause or predispose certain types of dementia
- identifying whether prolonged sitting in older adults increases the risk
- examining whether exercise can improve the cognitive and physical health of individuals at risk of dementia, such as those with Type 2 Diabetes or cognitive impairment
- determining the most beneficial level of intensity of activity to protect the ageing brain
- investigating the impact of multi-faceted exercise programs
- looking into links between sleep disturbance and dementia
- examining the relationship between chronic alcohol intake and alcohol-related dementia, and possible interventions
- searching for new dementia genes.
DEMENTIA LINKS TO EARLY LIFE STRESS

‘The ongoing effects of childhood stress need to be recognised and factored into dementia prevention and care, especially for groups at high risk of childhood adversity.’

DR KYLIE RADFORD
NHMRC-ARC DEMENTIA RESEARCH DEVELOPMENT FELLOW AND CLINICAL NEUROPSYCHOLOGIST
NEUROSCIENCE RESEARCH AUSTRALIA,
UNIVERSITY OF NEW SOUTH WALES
New research into dementia among Indigenous Australians shows that adverse experiences in childhood—such as poor health, moving frequently and being separated from family—impact emotional health and increase the risk of developing dementia decades later.

**FASTEST GROWING HEALTH CONCERN**

Indigenous Australians develop dementia at more than three times the rate, and often up to a decade earlier, than the rest of the population. (12 p.15)

It is the fastest growing health concern facing Indigenous Australians, and new studies from Neuroscience Research Australia (NeuRA) reveal that the risk is even greater for people who experienced trauma in childhood.

Head Researcher, Dr Kylie Radford, is an NHMRC-ARC Dementia Research Development Fellow at NeuRA, based at the University of New South Wales. She says that reducing dementia in Indigenous communities will require appropriate treatments and health care across the whole life course, starting with the prevention of adverse childhood experiences.

**THE IMPACT OF TRAUMA**

The team at NeuRA conducted a cross-sectional study of people living in urban and rural areas of New South Wales.

More than 300 Aboriginal and Torres Strait Islander participants between the ages of 60 and 92 completed a detailed survey about health and wellbeing, cognition and family history.

Participants also completed a detailed questionnaire about childhood trauma. Many reported early life experiences of poor health, constant moving, and separation from family, including as part of the Stolen Generation.

The results showed a clear link between the reporting of adverse experiences in childhood and subsequent diagnosis of dementia in later life. (13) This adds to a growing body of research linking childhood trauma to an increased risk of cognitive decline.

**MULTIPLE RISK FACTORS**

The study provided a snapshot in time of the health and wellbeing of Indigenous Australians with early cognitive decline, with consistent findings among participants from urban and remote areas.

In step with national statistics, ageing remains the number one risk factor for dementia in Indigenous Australians. However, the onset tends to start up to 10 years earlier.

Other leading factors contributing to the heightened risk of cognitive decline include lower levels of education, head injury and stroke.

As for the enhanced risk posed by trauma, researchers say the link could be direct or the result of multiple risk factors at play. Trauma can have very clear and damaging impacts on cognition. It can rewire neural networks and restructure or restrict growth of the brain.

Such damage can trigger symptoms such as inattention and impulsivity, and create emotional and learning difficulties that might then be exacerbated by other lifestyle risk factors, such as substance abuse.

‘The research highlights the need to focus on resources and early childhood intervention to support Indigenous families and communities,’ Dr Radford says.

The team at NeuRA will continue to track the research participants to deepen the understanding of the impact of childhood trauma as a predictor of dementia later in life, and work to convert their findings into culturally appropriate and accessible strategies to better prevent and treat dementia among Indigenous Australians.
ASSESSMENT AND DIAGNOSIS RESEARCH

WHY ASSESSMENT AND DIAGNOSIS RESEARCH IS IMPORTANT
Currently there is no single test that can accurately diagnose dementia.

In Australia, families begin noticing symptoms of dementia around one and a half years before the first health professional consultation. Firm diagnosis takes an average of just over three years, and even longer for people from non-English speaking backgrounds. (14 p.12)

This is partly due to the complexity of diagnosing dementia. Dementia needs to be distinguished from other conditions with similar features such as depression and anxiety, thyroid disease and many other medical conditions. There is also the problem of differentiating dementia from normal ageing. Even after a diagnosis of dementia, further work is needed to determine what type of dementia the person has.

Delays in diagnosis mean lost opportunities for earlier medical and social interventions for people with dementia and their families.

Timely diagnosis can allow the person with dementia to make choices about their future while they are still able, such as planning finances, powers of attorney and care in advance. It can also enable access to medications that may relieve symptoms and delay progression, as well as support from community services that can enable them to continue living in their community for as long as possible. (14 p.7)

Early diagnosis is the first step in managing dementia, and will be even more important in future, as more effective treatments become available.

Desired outcomes of assessment and diagnosis research
The desired outcomes for research in the priority area of assessment and diagnosis are:
• coordinated and supported diagnosis
• effective interventions to reduce the risk and lower the incidence of dementia.

Funded assessment and diagnosis research
There are 34 funded activities focusing on assessment and diagnosis.
This includes 27 fellowship grants, five project grants and two international collaboration grants across 14 universities and research institutions.

Examples of this research include:
• investigating new ways of predicting Alzheimer’s disease including iron content in the brain and biochemical changes in the blood
• assessing computerised assessments of psychological functions and state of the art brain imaging
• improving detection, identification, management and care in Indigenous communities
• investigating biochemical changes in the blood before symptoms appear, to identify biomarkers for early diagnosis of Alzheimer’s disease
• supporting early detection by studying ageing, genes and brain behaviour to identify younger people at risk
• improving timely diagnosis and best care for Aboriginal and Torres Strait Islander people living with dementia, through clinical education, tools to prompt identification of cognitive impairment, monitoring and feedback, and strategies to adhere to clinical practice guidelines
• undertaking a longitudinal study with a focus on translatable outcomes, examining the usefulness of selected screening tools and assessments for dementia in people with intellectual disability
• using new neuroimaging techniques to measure hallmark features of Alzheimer’s disease
• mapping the brain using computer modelling
• focusing on changes in the retina as an early sign.
INTERVENTION AND TREATMENT RESEARCH

WHY INTERVENTION AND TREATMENT RESEARCH IS IMPORTANT

Intervention and treatment can improve quality of life for people with dementia as well as their families and carers.

However, while existing medications may reduce dementia symptoms and improve quality of life in some people, there is currently no medication that stops the progress of the brain diseases that cause dementia. (4 p.11)

We need to accelerate discovery research to develop a strong pipeline of possible treatments ready for clinical trials. As there has yet to be a significant medical breakthrough in the prevention or treatment of dementia, it is important that this pipeline goes beyond existing drug targets and corresponding therapeutic strategies.

Drug discovery requires partnerships between universities and the pharmaceuticals industry as well as strong links to the international effort.

We need to identify new approaches to slowing and halting dementia’s progress, establish cellular and animal models, facilitate screening of compounds in those animal models, and also validate these new approaches.

Desired outcomes of intervention and treatment research

The desired outcomes for research in the priority area of intervention and treatment are that:

• new understanding informs approaches to treatment
• effective interventions sustain independence and improve quality of life and quality of care
• new innovative treatments delay or prevent dementia progression.

Funded intervention and treatment research

There are 40 funded activities focusing on intervention and treatment research.

This includes 37 fellowship grants, one large-scale project, one international collaboration grant and funding to the Clem Jones Centre for Ageing Dementia Research.

These activities are taking place across 14 universities and research institutions.

Examples of this research include:

• investigating possible new drugs
• developing an integrated network in Australia to maximise the outcomes of treatment for depression and anxiety in dementia
• optimising medicine regimens for people with dementia
• advancing knowledge of regulators in the brain that prevent the build-up of proteins associated with dementia
• studying the effect of disrupting certain proteins that could cause memory loss
• exploring the therapeutic potential of certain proteins
• understanding how copper-complexes reduce damaging inflammatory responses in novel human cell models of Alzheimer’s disease
• examining the role of specific DNA sequences
• investigating the use of brain stimulation techniques for the treatment and prevention of dementia
• investigating if therapies to restore myelin (the protective sheath around nerve fibres) could be effective against Alzheimer’s disease
• investigating whether oestrogen-based therapy may improve cognitive functioning in people with dementia.
IMPROVING DEMENTIA DIAGNOSIS

‘Dementia can affect things like recognising someone you know, understanding how they feel and being able to empathise with others.’

DR FIONA KUMFOR
SENIOR RESEARCH FELLOW, NHMRC-ARC DEMENTIA RESEARCH DEVELOPMENT FELLOW, CLINICAL NEUROPSYCHOLOGIST, UNIVERSITY OF SYDNEY
Prevalence studies indicate that frontotemporal dementia (FTD) could be the second most common form of dementia in individuals under 65, after Alzheimer’s disease. (15) While the underlying causes of the two diseases are distinct, both are common in people under 65 years of age, and can present with similar symptoms. This makes it difficult to accurately diagnose frontotemporal dementia.

BUILDING ON PAST WORK

Dr Fiona Kumfor, an NHMRC-ARC Fellow based at the University of Sydney, is building on her past research into how dementia affects memory to examine how FTD affects the way people experience and cope in social situations.

‘These are the abilities we usually take for granted, like recognising someone you know, understanding how they feel and being able to empathise with others,’ Dr Kumfor says.

The research aims to:

• understand the differences between FTD and Alzheimer’s disease for a more accurate diagnosis
• develop novel ways of testing how people function in social situations
• discover the neurobiological basis of complex social behaviours and cognition.

MAKING SENSE OF NEW BEHAVIOUR

While memory is often the first thing to change with Alzheimer’s disease, FTD harms the front of the brain, which governs personality and a person’s capacity to interpret and express emotion. This can be bewildering, and often sparks personality and behaviour changes that family and friends struggle to understand.

Through her fellowship, Dr Kumfor is studying the unique ways FTD shapes perceptions, moods and emotions.

DISTINGUISHING DEMENTIA TYPES

Recognising FTD symptoms depends on which part of the brain is damaged.

Damage to the frontal lobes can cause intellectual, behavioural, personality and emotional changes and is known as behavioural-variant FTD.

Damage to the temporal lobes can make it difficult to speak and recognise everyday objects and, in the case of semantic dementia for example, can lead to a gradual loss of language skills.

ASSESSING SOCIAL COGNITION

Recent research shows a connection between social cognition and FTD. People with behavioural-variant FTD and semantic dementia both experience an inability to recognise emotions—but it affects them differently. (16 p.1)

Most studies base their research on recognising emotion in faces without context. Dr Kumfor is investigating how putting faces into context can influence emotional recognition.

She has assessed people with behavioural-variant FTD, people with semantic dementia, and healthy people. The assessment was based on three tasks involving face alone, context alone and face embedded in context. Neuroimaging analyses identified correlation between shrinkage of brain regions and participants’ performance of the tasks.

All people with FTD were able to understand emotions better when the surrounding contextual information (such as body language) was emotionally similar. However, people with behavioural-variant FTD performed worse when dealing with incongruent situations. Neuroimaging analysis showed abnormalities in these people that indicate they are too dependent on external contextual information (17).

POTENTIAL FOR NEW TREATMENTS

Dr Kumfor’s research shows that people with FTD struggle with learning, recognising new people and understanding social cues in ways researchers have previously underestimated. This inability to understand social cues is a marker for FTD that has not previously been recognised. The findings offer new potential for better diagnosis and treatment of people with different types of dementia.
A NEW DRUG TARGET FOR ALZHEIMER’S

“We thought there must be another factor in addition to amyloid driving the path to symptoms of Alzheimer’s. We’ve identified that factor is excess iron.”

DR SCOTT AYTON
NHMRC-ARC DEMENTIA RESEARCH DEVELOPMENT FELLOW, NEURODEGENERATION DIVISION, FLOREY INSTITUTE OF NEUROSCIENCE AND MENTAL HEALTH; UNIVERSITY OF MELBOURNE
In early 2017 Dr Scott Ayton and the Florey Institute of Neuroscience and Mental Health attracted widespread attention after identifying that excess iron in the brain contributed to the symptoms and progression of Alzheimer’s disease. Now, they are undertaking clinical trials to investigate whether lowering iron levels may delay or halt the onset of dementia.

**MORE THAN β-AMYLOID**

Researchers have long understood the relationship between the protein β-Amyloid and Alzheimer’s disease. While every person who has Alzheimer’s disease has amyloid pathology, not all those with amyloid go on to quickly develop Alzheimer’s. Dr Ayton and his team investigated if there were further contributing factors, and identified that excess iron in the brain may be the missing link.

**THE INITIAL RESEARCH**

Working with CSIRO and using specifically tuned medical resonance imaging (MRI), Dr Ayton and his team conducted brain scans of 117 people with dementia. Their findings indicated high levels of iron in the hippocampus act together with amyloid to speed up the progression of dementia (18).

**THE ROLE OF IRON**

Iron is critical to the functioning of a healthy human body, assisting with providing the energy the body needs. When excess levels of iron are found beyond the blood and in the brain, however, the effects can be dangerous. As well as dementia, associated diseases from excess brain iron also include Huntington’s disease and Parkinson’s disease.

Dr Ayton notes that iron is highly reactive, so probably subjects neurons to chemical stress, damaging them in the same way that iron metal rusts in the presence of oxygen.

Effectively this means excess iron could be causing the brain to ‘rust’, acting in addition to β-Amyloid to speed up the progression and development of Alzheimer’s. However, Dr Ayton explains there is no evidence that the amount of iron we eat, or the amount measured in our blood, has any impact on the amount of iron in our brains.

‘So we are not recommending people change what they eat based on our research,’ Dr Ayton says.

**CLINICAL TRIALS**

The team is now turning its attention to available drugs, conducting clinical trials to investigate whether lowering iron levels may delay or halt the onset of cognitive impairment.

At the heart of the trial will be the existing drug deferiprone, which acts to mop up excess iron in the brain.

‘Given the data from our study, it seems reasonable to hypothesise that lowering iron in the brain would slow the progression of the disease, but we can only know that by testing it, which is what we are now going to do,’ Dr Ayton says.

**THE ULTIMATE OUTCOME**

If successful, Dr Ayton’s trials will pave the way to better strategies for identifying and treating Alzheimer’s disease.

Not only would medical practitioners be able to predict the likelihood of developing Alzheimer’s by testing for levels of excess brain iron, they could also use drugs to reduce iron levels to effectively delay or stop cognitive decline.

‘We foresee a future where we will measure brain iron with MRI, and those people with excess brain iron can take a drug to lower the amount,’ Dr Ayton says.

‘We won’t know until the trial how effective lowering brain iron may be. But, if it is effective, we may be able to slow the onset of Alzheimer’s and maintain cognitive function for longer.’
LIVING WITH DEMENTIA RESEARCH

WHY LIVING WITH DEMENTIA RESEARCH IS IMPORTANT

People with dementia can experience stigma and social exclusion. Improved community awareness and understanding about dementia is important so that people living with dementia and their carers feel more supported and connected.

In addition, knowledge of dementia and the rights of people with dementia is sometimes lacking. People with dementia are often excluded from decision-making about their own care, rehabilitation or proactive interventions to make the most of their available capacity.

Consumers need the opportunity to contribute to understanding of dementia and to co-design research and service solutions.

Increased consumer participation in clinical trials is also important to allow earlier access to innovative treatments and care, and collaborative care decision-making.

Research in the area of living with dementia can help to improve the rights, quality of life and social inclusion for people with dementia, their families and carers. It can also improve their interactions related to prevention and awareness of risks through to diagnosis and care.

Desired outcomes for living with dementia research

The desired outcomes for research in the priority area of living with dementia are:

- increased awareness and understanding of the rights, needs and experiences of people with dementia living in the community
- support for their dignity, independence and self-determination.

Funded living with dementia research

There are 15 funded activities focusing on living with dementia.

This includes 11 fellowship grants and four large-scale project grants across nine universities and research institutions.

Examples of this research include:

- studying the impact of music therapy, group singing and choir participation on dementia symptoms and quality of life
- looking into ways to help people with dementia make decisions about when to stop driving, and to deal with the practical and emotional challenges
- promoting advanced care planning, testing rehabilitation options
- studying how and why music can help people with dementia and their carers
- better understanding issues for people with dementia and other chronic medical conditions
- developing strategies to prevent falls and further functional decline
- developing better management options for people living with dementia by learning about their movement around the house and their ability to make decisions
- investigating how those at risk of dementia explore the world visually, and how this changes over time (more than half of the people living with Alzheimer’s disease experience visual impairments)
- examining whether videoconferencing is an effective way of delivering an evidence-based intervention that delays functional decline
- encouraging people with dementia and Parkinson’s disease to enrol in a brain donation program, allowing detailed information for future correlations between symptoms and brain changes
- establishing networks with health professionals as ‘agents of change’ to improve care practices in their organisations.
WHY CARE RESEARCH IS IMPORTANT

Dementia is a major cause of disability and dependency among older people. It has a significant impact not only on individuals but also on their carers, families, communities and society more broadly.

National guidelines for aspects of managing dementia in Australia have recently been introduced. However, many of the recommendations for practice are based on consensus and not rigorously evidenced. Management and care of people with dementia in Australia varies, with scope to improve the consistency and quality of care.

Care for people with dementia depends on their individual situation and includes physical, social, cultural and mental wellbeing.

Research into quality dementia care and the best ways of supporting carers provides important insights into improving quality of life of people with dementia, their families and carers.

This includes identifying effective ways of translating and implementing dementia care research into various settings such as hospitals, communities, aged care facilities and general practice.

It is important that quality care extends from the first time symptoms are reported through to providing information, making changes and offering strategies for care before moving to medication. Care workers should also be trained in dementia care, and people with dementia should be encouraged to keep healthy, active and connected in their local community. Carer and family support is also important.

Desired outcomes of care research

The desired outcomes for research in the priority area of care are:

- improved quality of life and care for people with dementia and their carers through high quality clinical care in all environments
- a multidisciplinary approach to individualised care
- consumer choice to drive improvements.

Funded care research projects

There are 14 funded activities focusing on care research. This includes eight fellowship grants and six large-scale project grants across 10 universities and research institutions.

Examples of this research include:

- measuring the effectiveness and cost-effectiveness of treatments and care packages
- trialling education and training for frontline home carer workers
- building capacity and resilience in the care workforce
- aiming to better understand the factors that contribute to depression and other behavioural symptoms in people with Alzheimer’s disease
- exploring how medications impact on quality of life of aged care facility residents
- systematically investigating the impact of hospitalisation
- trialling the effectiveness of new models of care at home
- developing an electronic nursing assessment system for people admitted to hospital
- piloting clinical quality registries to collect health data about the quality of clinical care
- trialling training for residential aged care staff to manage behavioural problems of residents with dementia, such as wandering or sleep disturbance
- developing and testing a culturally based enhancing quality of life tool for Aboriginal Australians living with dementia.
MEMORY THROUGH MUSIC

‘Music has the power to evoke feelings and spark memories in a way no other stimulus can.’

DR AMEE BAIRD
NHRMC-ARC DEMENTIA RESEARCH DEVELOPMENT FELLOW
AND CLINICAL NEUROPSYCHOLOGIST, MACQUARIE UNIVERSITY
Music activates the brain in a unique and powerful way: it stirs emotion, sparks nostalgia and can have a profound impact on the capacity for remembering. Dr Amee Baird is studying how music can bypass cognitive impairment to trigger lost memories in people with Alzheimer’s disease and other types of dementia.

**THE POWER OF MUSIC**

Music crosses cultures, language and generations. It elicits emotional and physical responses, engaging the brain to recall, feel and react in a way nothing else can.

Dr Baird became interested in the power of music after reading about retired musicians with Alzheimer’s disease who still loved to play their instruments, and did so with the same fluency as ever.

‘It shows that the parts of the brain that control memory for music and the ability to sing are not as affected by dementia. Somehow music remains; music abilities are preserved,’ Dr Baird says.

This is not only the case for professional musicians. There are many instances of people with advanced dementia who can recite the latest chart-topping songs or learn a new instrument.

Dr Baird believes this ability may come down to implicit memory, in particular ‘procedural’ memory. This unconscious form of memory is responsible for us remembering how to do things, such as playing an instrument. This type of memory remains intact in people with Alzheimer’s disease, whereas ‘explicit’ memory, such as the conscious recall of when or where we heard a song, is typically impaired.

**THE REMINISCENCE BUMP**

The music we hear during our youth is most likely to evoke memories later in life. Dr Baird attributes the significance of songs from our adolescence and early adulthood in triggering memories to the phenomenon of the ‘reminiscence bump’, the peak time for autobiographical memories.

‘It’s a seminal time when we’re deciding what we like, establishing self-identity, and often finding our first love,’ Dr Baird says.

**INSIDE THE BRAIN**

Brain scans support the wide-ranging impact music can have.

‘Neuroimaging research shows music provides a “super stimulus” for the brain,’ Dr Baird explains. ‘It activates widespread brain regions, including parts controlling movement, emotion and memory. Familiar and favourite songs can also powerfully engage the frontal regions of the brain, which are typically spared of the pathology of Alzheimer’s disease.’

**HARNESSING MUSIC TO ASSIST PEOPLE WITH DEMENTIA**

Dr Baird is researching new ways to deliver the therapeutic benefits of music in a group program, ‘Music Mind and Movement (MMM)’ to people in aged care facilities. She is also investigating how music and other types of auditory stimuli like familiar voices can affect behaviour and brain responses in people with severe dementia who are unresponsive or have lost verbal communication skills.

She has met some inspiring musicians with dementia, and is following them over time to compare their music abilities with other cognitive skills.

Research to date indicates music can have a host of benefits for people with dementia. (20)

Not only does music have the potential to ‘remain an island of preservation’ in an otherwise cognitively impaired person’ as Dr Baird describes, it is also a powerful tool for calming stress and anxiety, for people with dementia and their carers.
IMPROVING CARE TO REDUCE BEHAVIOUR SYMPTOMS

‘Australia urgently needs better programs to support residential aged care facilities to manage behaviour symptoms of dementia.’

DR MOYRA MORTBY
NHRMC-ARC DEMENTIA RESEARCH DEVELOPMENT FELLOW,
SCHOOL OF PSYCHOLOGY, FACULTY OF SCIENCE,
UNIVERSITY OF NEW SOUTH WALES
In residential aged care, many people experience behavioural and psychological symptoms of dementia (BPSD) such as aggression, agitation or disinhibition. Using an evidence-based approach, an Australian study is developing and trialling a staff training program designed to provide aged care staff with a better understanding of behavioural problems in dementia.

**CHALLENGING BEHAVIOUR**

Between 56 and 90 per cent of Australians with dementia exhibit clinically significant behavioural and psychological symptoms of dementia, with higher rates occurring in residential aged care facility settings. (21 p.49, 52)

Physical aggression, agitation and disinhibition—especially when severe—are difficult to manage and can put people with dementia, carers and other residents at risk. Likewise apathy and depression cause considerable discomfort to residents and require a skilled approach to manage them effectively.

‘Not only the person with dementia but also other residents, family and staff find these symptoms disturbing,’ says Dr Moyra Mortby of the School of Psychology, University of New South Wales.

Dr Mortby is leading a collaborative project with Goodwin Aged Care in Canberra to improve care and quality of life for residents with dementia-related behavioural problems. It will equip staff with skills to better identify and manage such behaviours using non-pharmacological interventions, improve wellbeing of care staff, foster better relationships between care staff and residents, and improve quality of life for people with dementia living in aged care.

**SPECIALISED TRAINING AND STRUCTURED INTERVENTION**

Approximately 300 residents and care staff at three Goodwin Aged Care facilities across Canberra are participating in the study. Each staff member is paired with a resident and completes all assessments and intervention sessions for that resident.

Staff are trained in using a standardised approach to identify and manage BPSD. This involves inventories, checklists and screening scales to determine the presence and severity of BPSD as well as potential causes, including other possible physical or medical causes such as pain or infections. Care staff then use a flowchart to select the most appropriate, non-pharmacological intervention.

Staff are trained in delivering these interventions, which include exercise, massage and touch, reminiscence therapy, music therapy, and meaningful and pleasant activities (identifying and implementing activities that are meaningful to the resident with dementia by creating a sense of connection and belonging, while also promoting autonomy and personal identity).

**A PERSON-CENTRED APPROACH**

The project will evaluate the efficacy of the BPSDPLUS Program, a person-centred intervention program developed by Dr Mortby, to reduce the prevalence of BPSD and medication use in Australian residential aged care facilities using non-pharmacological interventions.

‘International good practice guidelines recommend the use of non-pharmacological interventions as the first-line of treatment for BPSD, while pharmacological interventions are considered second-line treatments,’ explains Dr Mortby.

‘Despite little evidence of effectiveness and high rates of adverse effects, pharmacological methods are still commonly used to manage BPSD. The discrepancy between international and national recommendations and the continued over-prescription of medication to manage BPSD must be addressed.’

**PROACTIVE CARE AND IMPROVED QUALITY OF LIFE**

‘This program will equip Australian staff working within residential aged care facilities with the specialised training and skills needed to provide care proactively for all residents with BPSD and improve quality of life for residents, carers and relatives,’ Dr Mortby says.

‘The BPSDPLUS Program offers a proactive response to BPSD, rather than the current reactive response. The unique contribution of this research is the evaluation of the impact of the BPSDPLUS Program on residential aged care facility staff, their attitudes towards dementia care and quality of interactions with residents.’
COLLABORATION AND PARTNERSHIPS

An essential part of the Boosting Dementia Research Initiative is coordinating national research activities and integrating with international efforts.
BRINGING STAKEHOLDERS TOGETHER

The NNIDR is developing partnerships between dementia research stakeholders including collaboration and coordination among researchers, as well as between researchers, consumers, industry, health professionals and philanthropic organisations.

National activities

The NNIDR supports and participates in a range of national activities, such as the:

- **Australian Dementia Forum.** The NNIDR held its inaugural forum in May 2016, attracting more than 150 attendees, covering the full spectrum of dementia research in Australia, and sparking important collaborations. The second forum in October 2017 attracted 250 attendees and updated participants on early outcomes of the Boosting Dementia Research Initiative.

- **National Consumer Summit.** Dementia Australia convened this summit in March 2016, bringing together people with dementia and their carers to identify areas of focus for a National Strategy for Dementia.

- **NNIDR Dementia Care Forum.** In October 2017 the NNIDR delivered the Government’s election commitment to consider and decide on actions for involving people with dementia and their families and carers in dementia care research.

- **Caring for cognitive impairment campaign.** The NNIDR is a support organisation for this Australian Commission on Safety and Quality in Health Care campaign for hospitals to commit to high quality care for people with cognitive impairment, including dementia.

There are also opportunities for new and creative partnerships, in particular through Dementia Australia, which actively promotes research projects to its stakeholders, and through the NNIDR’s Board, which has strong representation from the private sector, commercialisation and philanthropic interests.

International activities

The NNIDR supports international collaboration and partnerships through activities related to the:

- **European Union Joint Programme—Neurodegenerative Disease Research (JPND).** The NNIDR contributes to international strategic decision-making through Board membership of JPND, including determining research priorities and developing funding calls.

- **International Research Network for Dementia Prevention.** The NNIDR has supported the development of this network through the Dementia Collaborative Research Centre.

- **Alzheimer’s Research UK (ARUK).** The NNIDR has developed a relationship with ARUK, initially to support and promote its ‘Target Validation Pathfinder Grant’ scheme among Australian dementia researchers. The scheme links researchers with ARUK’s drug discovery Institutes and funds pre-clinical target validation.

- **World Health Organisation (WHO).** The NNIDR has a leadership role in Australia’s participation in WHO’s dementia initiatives and in providing important research activity data for monitoring progress towards cure and care worldwide.
**Collaborative research**
Projects funded under the Boosting Dementia Research Initiative are drawing Australian dementia researchers together. The various funding programs, with the exception of the Fellowships, are set up for collaborative teams to combine and make the most of different types of knowledge and experiences. Funded projects already include several national and international collaborative research efforts. Fellows are brought together regularly to discuss progress and develop collaborations addressing the NNIDR’s Strategic Roadmap.

**Assessment and diagnosis research**
Collaborative research in the priority area of assessment and diagnosis includes the European DNA bank project. This project is assisting two major Australian studies to partner with a large European consortium to improve knowledge of the genetic factors related to risk of developing dementia.

Another example is the work being done by the BRIDGET consortium. This international collaboration aims to identify genetic variants that are associated with structural brain ageing, cognitive performance, and dementia risk in Australian and international population samples.

In another funded project, an international consortium of clinics is working together to improve understanding of how to best assess, diagnose and treat frontotemporal dementia by optimising speech assessment and treatment.

**Living with dementia research**
Collaborative research in the priority area of living with dementia is focusing on improving quality of life for people with dementia and their informal caregivers in rural and regional communities. Led by researchers at the University of Newcastle, this project involves establishing an international Community of Practice to focus on adapting a web-based program designed by European researchers to the Australian context.

**Care research**
Boosting Dementia Research Initiative funding is bringing together communities of practice in the priority area of care research. Communities of practice link multidisciplinary teams within the health system to improve health and quality of life of people with dementia and their carers. End users are driving research across four key themes of developing measures for assessing unmet needs, exploring barriers to service delivery, exploring medico-legal and financial impediments to providing care, and testing innovative strategies to improve health outcomes for people with dementia and their carers.
'There are solid increases in dementia related outputs even among those Australian institutions outside of the 12 key institutions that were highlighted for having notable NHMRC funding for dementia research since 2016. The improvements in this second cohort suggest a broader national trend favouring research related to dementia...[This suggests] a change in behaviour and priorities even within non-recipient institutions.'

Thomas Barlow
NNIDR: Dementia Bibliometric Report 2017
[internal report commissioned by the NNIDR]
EYE SCANNING FOR ALZHEIMER’S

‘Changes in the eyes can tell us a lot about changes also happening in the brain’.

DR MOJTABA GOLZAN
NHMRC-ARC DEMENTIA RESEARCH DEVELOPMENT FELLOW,
UNIVERSITY OF TECHNOLOGY SYDNEY
Imagine if your eye specialist could spot the early signs of cognitive decline as part of your regular check-up. At the University of Technology Sydney, Dr Mojtaba Golzan is mapping how changes in brain tissue present subtle changes to the retina, with the aim of creating a simple eye-scan that can detect Alzheimer’s disease.

**A WINDOW TO THE BRAIN**

Vision scientist Dr Golzan is tracking how particular characteristics in the eyes correlate with changes in the brain.

He is creating a panel of specific signs that clinicians can look for to identify different dementias through an eye scan alone.

‘We call the eyes a window to the brain because through eye scans, we can extract information that indicates brain changes characteristically linked with dementia or other cognitive conditions,’ Dr Golzan explains.

**A HIDDEN CODE**

The research focuses on specific characteristics, known as optical biomarkers, situated in the retina at the back of the eye.

Three markers of particular interest are:

- structural—eye tissue
- functional—eye operation
- vascular—eye blood circulation.

By tracking and comparing changes in the retina with changes in brain tissue, scientists can begin mapping distinctive links between various biomarkers and cognitive pathologies such as Alzheimer’s disease.

Through the NHMRC-ARC Dementia Research Development Fellowship, Dr Golzan is cataloguing a series of optical biomarkers to help with early screening and diagnosis of Alzheimer’s disease.

If successful, this research will provide a model for creating similar screening tools to assist with early detection of other cognitive pathologies in the future.

**EARLY RESULTS AND NEXT STEPS**

Dr Golzan and his team are now at the midway point of the fellowship project.

They are conducting clinical and animal trials, which so far have revealed a clear distinction between the vascular parameters in an established Alzheimer’s group compared with a control group. (22, 23)

Moving into the next phase, Dr Golzan will begin a longitudinal study with people currently experiencing mild cognitive impairment or in the early stages of Alzheimer’s disease.

He will also run a parallel animal study to further establish such links between changes in the retina and brain.

Through the study, scientists will track changes and measure biomarkers in the eye over time, using data from the Alzheimer’s group to effectively arrange recognised optical biomarkers into further sub-classifications.

**LIFE-CHANGING EARLY DETECTION**

Through the research into optical biomarkers, Dr Golzan aims to create an eye scan that can help health care professionals screen for and identify Alzheimer’s disease—even predicting the stage of the disease and how quickly it is likely to progress.
LOOKING FORWARD

Priorities for the future include communicating outcomes and building on successes to further enhance collaboration in dementia research.
CONTINUE TO STRATEGICALLY INVEST IN BOOSTING DEMENTIA RESEARCH

A robust, national, evidence-based and long-term approach to the diagnosis and treatment of dementia is essential to the social and economic wellbeing of Australia. An appropriately constructed and targeted research and translation strategy underpins more effective health service delivery and intervention design, and drives the delivery of better treatments. This improves 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, leading to a slowing of the onset of dementia, 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 by keeping individuals in employment for longer, minimising the need for carers to leave work, and maximising clinical outcomes at the best possible cost.

Through the Boosting Dementia Research Initiative, Australia joins the significant effort across the globe, as expressed at the G8 Dementia Summit in 2013, to drive forward progress in finding cures or disease-modifying therapies for dementia by 2025. (24)

BUILD ON SUCCESSES

There is also the opportunity to build on success already achieved through NNIDR membership, recruitment and engagement with stakeholders. This includes capitalising on the dynamic, interactive virtual platform co-designed by NNIDR members, to further enhance collaboration and coordination of dementia research.

The NNIDR will also continue to pursue emerging opportunities at the Australian and international levels for advancing new drug discovery for dementia.

Another priority is ensuring the health systems applies the considerable portfolio of research outcomes achieved by the Dementia Collaborative Research Centres and the Cognitive Decline Partnership Centre. In particular this will involve working with Dementia Australia and other health stakeholders to examine how to best implement research outcomes and translate knowledge into policy and practice.

A new partnership is developing between the NNIDR and Dementia Training Australia to maximise opportunities for communicating well-evidenced research via training programs that will guide health care practice and contribute to quality of life for people with dementia, their families and carers.

Other goals include providing continued advice to the NHMRC on dementia research and priorities to deliver the NNIDR’s Strategic Roadmap, working with other key agencies to ensure dementia research is advanced as part of their research and development programs, and continuing to build strategic alliances with other dementia research funding initiatives and agencies around the world.

COMMUNICATE OUTCOMES AND IMPACT

A priority of the Boosting Dementia Research Initiative is to clearly communicate the outcomes and impact of Australia’s significant investment in boosting dementia research.

With the first fellowships and team grants now reaching the end of their second year of funding, it is time to begin sharing research findings. This report is part of that process.

‘Australian research relating to dementia has grown especially strongly in high impact journals and via publications involving high-status international co authors…Australia also increased the international connectivity of its research faster than the underlying global trend.’

Thomas Barlow
NNIDR: Dementia Bibliometric Report 2017
[internal report commissioned by the NNIDR]
## APPENDIX A
### RESEARCH FUNDING AWARDED TO DATE

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<td>Sleep, plasticity and neurodegeneration: Targeting sleep to improve cognition in Mild Cognitive Impairment (MCI)</td>
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<td>Dr Lisa Kalisch Ellett University of South Australia</td>
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<td>Predicting perioperative cognitive disorders in the elderly based on cardiovascular risk, AD risk and new biomarkers</td>
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<td>Comprehensive risk prediction models and presymptomatic biomarkers for dementia</td>
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### Table: Boosting Dementia Research Initiative

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<td>Optimising exercise prescription for brain health in older adults at risk of dementia</td>
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<td>Dementia associated to diabetes: prevention through the modulation of cerebrovascular integrity</td>
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<td>Prospective Imaging Study of Ageing: Genes, Brain &amp; Behaviour</td>
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<td>What can tau deposition tell us about the appearance of subjective and objective cognitive decline in older adults?</td>
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<td>Combined TMS-EEG for early diagnosis of Alzheimer’s disease</td>
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<td>Cognition in Motion: Characterization and Evolution of Cognitive Dysfunction in Motor Neurodegeneration and Frontotemporal Dementia</td>
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<td>Cross-comparison, validation and performance of computerised neuropsychological assessment devices in the evaluation of mild cognitive impairment and dementia</td>
<td>Dr Nicole Kochan University of New South Wales</td>
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<td>Lewy bodies in patients with dementia— Determining common and unique mechanisms in relation to Alzheimer’s disease</td>
<td>Dr Sivaraman Purushothuman, University of New South Wales</td>
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<td>BRIDGET: Brain imaging, cognition, Dementia and next generation GEnomics: a Transdisciplinary approach to search for risk and protective factors of neurodegenerative disease</td>
<td>Professor Perminder Sachdev, University of New South Wales</td>
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BOOSTING DEMENTIA RESEARCH INITIATIVE