



Australian Government

NHMRC National Institute for Dementia Research

STRATEGIC ROADMAP FOR DEMENTIA RESEARCH AND TRANSLATION

Understanding causes. Delayed disease onset. Earlier diagnosis. Delayed disease progression.
Optimal care every day.

EVERY THREE SECONDS
SOMEONE
IN THE WORLD
DEVELOPS
DEMENTIA

MORE THAN 46 MILLION
PEOPLE ARE
LIVING WITH DEMENTIA
WORLDWIDE
+ 9.9 MILLION
JOIN THIS NUMBER
EACH YEAR

MORE THAN 436,000
AUSTRALIANS ARE
LIVING WITH DEMENTIA
+ 240 PEOPLE
JOIN THIS NUMBER
EVERY DAY

SECOND LEADING
cause of death
IN AUSTRALIA

LEADING
cause of death
FOR WOMEN
IN AUSTRALIA

APPROXIMATELY 300,000
AUSTRALIANS
ARE CURRENTLY
CARING
FOR A PERSON
LIVING WITH DEMENTIA

Five years on from the announcement of the Australian Government's Boosting Dementia Research Initiative and with evidence of a significant boost underway,¹ this revision of the 2017 Strategic Roadmap for Dementia Research and Translation takes advantage of emerging strengths and new knowledge to deliver greater focus to, and impact from, the Australian dementia research effort. The need to address all aspects of the challenge continues to be recognised. Increased emphasis and priority is placed on improving outcomes for Aboriginal and Torres Strait Islander Australians, and on the need to retain and develop the new research capacity introduced to the sector.

GUIDING PRINCIPLES

Roadmap implementation will take into account the need to:

- Address all stages – causes, prevention, cure and care
- Involve people living with dementia, carers and families in all aspects of research
- Recognise and respond to Australia's cultural and linguistic diversity
- Ensure international collaborations
- Innovate and discover
- Achieve impact
- Partner across sectors and disciplines
- Determine and respond to vital dementia research infrastructure needs
- Provide open access to dementia research data

PURPOSE

The Strategic Roadmap for Dementia Research and Translation guides the dementia research sector in meeting the urgent challenge that dementia presents to Australia's health, economy and society. The Roadmap is a living document that takes account of progress to date, research gaps and emerging priorities. It is informed by researchers, clinicians, government, people living with dementia and their carers and families, the volunteer and community sector, and industry stakeholders.

PROGRESS TO DATE

With the announcement of the Boosting Dementia Research Initiative in 2014, the Australian Government has invested an additional \$200 million in dementia research, and established the NHMRC National Institute for Dementia Research (NNIDR). This has produced significant advances across the research spectrum, from increased understanding of disease mechanisms to diagnosis, drug discovery, clinical treatment, quality care, and risk reduction and prevention.¹ The sector has grown to be a high achieving and highly respected body of researchers operating with new scale and focus, across disciplines. This is evidenced by high quality publications, ground-breaking research outputs, and the leveraging of new funding sources.

Sources: Alzheimer's Disease International
The National Centre for Social and
Economic Modelling NATSEM (2018)
Dementia prevalence data 2018-2058
Australian Bureau of Statistics (2018)
Causes of Death, Australia 2017

FUTURE PRIORITIES

Improving Dementia Diagnosis and Prevention

There are more than 100 different forms of dementia and people often have significant comorbidities. As risk reduction measures vary according to individual circumstances and neuropsychiatric symptoms, accurate diagnosis is the first step to reduce risk and delay disease progression.

Diagnosis

There is no single, reliable and conclusive diagnostic test for dementia. There are many potential causes,² dementia overlaps with other chronic medical conditions, and the onset of symptoms is slow. Diagnosis currently takes an average of three years but can take up to seven years.

Investments to date demonstrate that earlier diagnosis will mean disease-modifying drugs and person-specific risk reduction regimes have potential to achieve a delay in disease progression. Australian researchers are developing personalised, non-invasive diagnostic approaches. Simple-to-collect blood and saliva tests, non-invasive imaging, new and large-scale genetic profiling, and whole-of-population data analyses are either in development, implementation-ready or underway. The recently established Australian Dementia Network (ADNeT) provides new capability for an unprecedented standard of early and accurate diagnosis.

Rapid and accessible diagnosis will require partnerships with industry to further develop screening tools, and engagement across the health system to deliver evidence-based models for dementia detection and early intervention.

Prevention

DEMENTIA
cost an estimated
US\$1 TRILLION
WORLDWIDE
LAST YEAR

\$120.4 BILLION
savings in Australia
BY 2056 FROM A
5% REDUCTION IN
incidence rates* of
DEMENTIA

* in people aged 65 years and over
Source: Alzheimer's Disease International
The National Centre for Social and
Economic Modelling NATSEM (2016)
Economic cost of dementia in Australia

The Lancet Commission on Dementia Prevention, Intervention and Care has demonstrated that lifestyle factors affect an individual's risk of developing dementia.³

There is now a greater, but by no means complete, understanding of how genetics, interventions, and environmental exposures interact to increase or reduce vulnerability. Particular intervention targets, strategies, and changes to the timing and duration of treatments are being investigated to develop effective dementia risk reduction regimes.

Creation of this evidence base will determine the health system measures and population level behavioural changes needed to prevent dementia by reducing risk. Importantly, a more precise understanding of major modifiable risk factors for various dementia types will offer new opportunities to prevent or delay onset. Strategic partnerships with chronic disease peak bodies and prevention programs, which target shared modifiable risk factors, will significantly strengthen and advance this work.

New targets, technologies and drug candidates

Diagnosis, prevention and treatment require a fundamental understanding of the causes and drivers of different forms of dementia.

With innovations in modern neuroscience research, it has become possible to more fully explore the complexity of the brain using novel, high precision approaches, such as gene editing, stem cell models, and whole genome analysis. New imaging technologies and data capabilities are bringing further innovations to the field, revolutionising research in neurodegeneration.

Despite this, discovering treatments for dementia requires a much deeper understanding of the biology of how dementia develops than currently available. Continued investigation is required to:

- identify the separate and shared characteristics of neurodegenerative diseases
- understand and target fundamental biological pathways
- identify new ways to intervene in the disease process
- pioneer new therapeutic interventions.

Further research into novel drug delivery methods, such as the use of ultrasound and nanotechnology, is also needed to ensure treatments reach the targeted areas of the brain.

This work demands wide-ranging collaboration and partnerships across sectors and disciplines. Access to vital dementia research infrastructure, including technology, data, and brain tissue resources will ensure dementia clinical trials can be advanced with full effect. In addition, the national health system will need to be ready to support the demand for, and delivery of, a significant disease-modifying therapy.

Improving quality of life and provision of care

Until effective treatments for dementia are found, many Australians will be significantly impacted by dementia either as a person with the disease, as a carer, family member, friend or community member. Research is underway that will inform health care and strengthen those social support processes that respond to the individual needs of people living with dementia. This will in turn drive quality improvement in care provision. Research topics range from methods to improve and provide consistent, equitable and high-quality care at the right time, to identifying more robust ways to address changing needs over the disease course, and developing allied health interventions to support quality of life for people with dementia and their carers.

\$15.5 BILLION
the expected
COST THIS YEAR OF
DEMENTIA
in Australia

INFORMAL CARE
is estimated at
82 BILLION HOURS
per year globally

NEARLY THREE-QUARTERS
OF THESE HOURS
are supplied by
WOMEN

Source: Alzheimer's Disease International
The National Centre for Social and
Economic Modelling NATSEM (2016)
Economic cost of dementia in Australia

There is an urgent need to continue building the evidence base, making sure that all research includes implementation strategies that will fundamentally improve health care models and care pathways, improving quality of life and creating efficiencies between the health and social care systems. The goal of living well at home for longer will require support and interventions that make the home, community and formal care environments more dementia-friendly. Unpaid carers play a crucial role in the dementia care system and not enough is known about how to support their varied needs. Research must also deliver ways to achieve the

widespread adoption of new evidence, for example through a better understanding of the financial cost and other resourcing issues involved in system change.

Aboriginal and Torres Strait Islander Australians and Dementia

Dementia is experienced by Aboriginal and Torres Strait Islander Australians at a much higher rate and with an earlier onset than in the broader community.^{4,5} Research is underway to develop new culturally safe and appropriate care models, cognitive assessment and quality of life measurement tools, and evidence-based strategies to promote healthy brain ageing.

An Aboriginal and Torres Strait Islander Roadmap for Dementia Research and Translation is being developed to prioritise this work and identify gaps for future attention. A strengths-based and healing-centred approach is being taken to address five priority areas:

- health literacy
- prevention, risk reduction and diagnosis
- access to services and supports
- culturally informed services and workforce
- end of life care.

Aboriginal and Torres Strait Islander knowledge systems and the importance of country are key considerations, as is delivering optimal access to the highest standards of diagnosis, treatment and care.

Retaining and building Australia's dementia research capacity

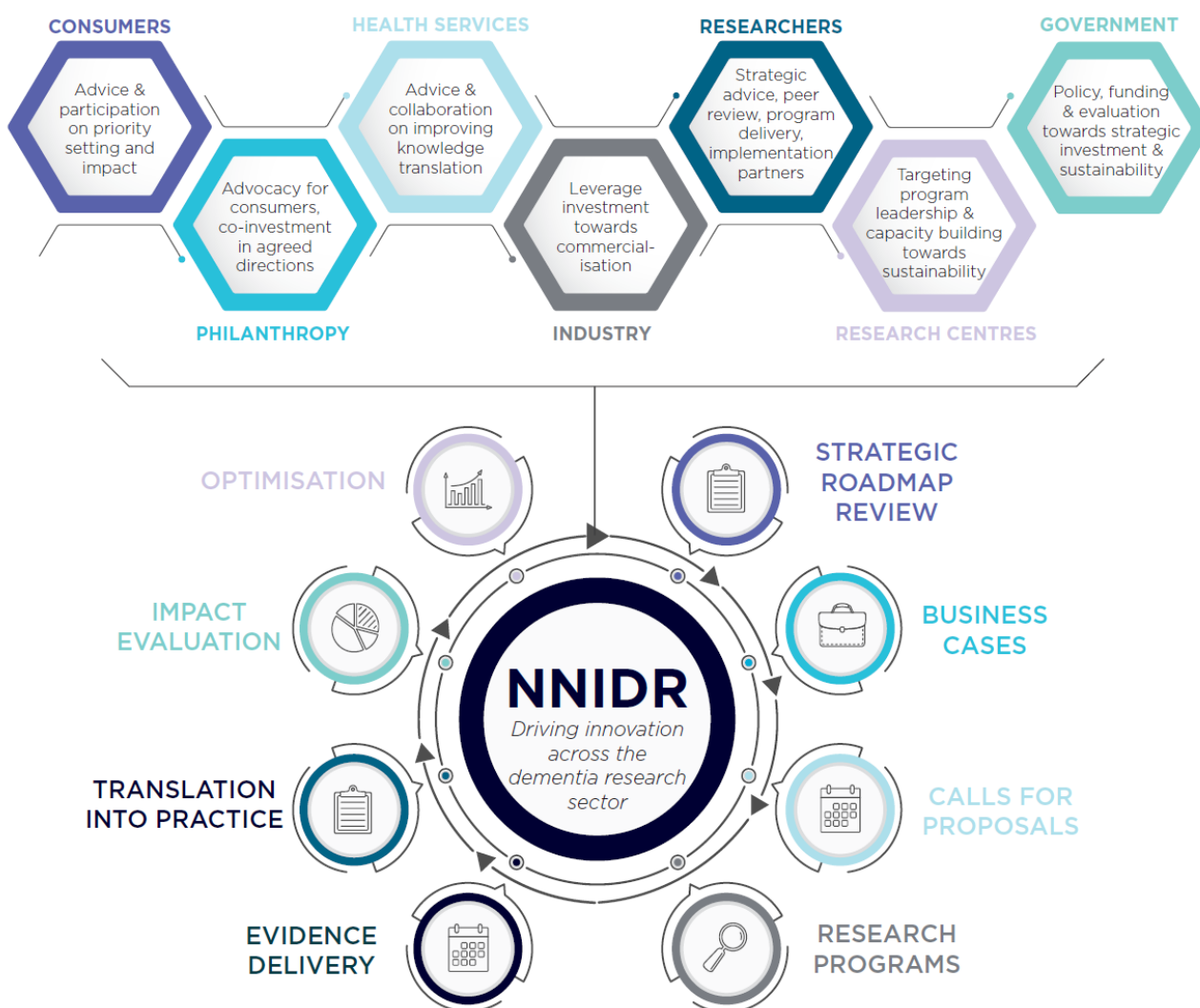
NNIDR brings together Australia's national health and medical research funding agency, the National Health and Medical Research Council (NHMRC), and the national peak body representing people living with dementia, their carers and families, Dementia Australia. This relationship embodies an international trend toward non-government organisation involvement in catalysing dementia research, fostering unique partnerships across diseases, national borders, and stakeholders, and providing swift and flexible research funding that complements funding from governments and industry.⁶

Under the Boosting Dementia Research Initiative, new researchers from other disciplines and disease areas have joined the dementia research effort, research teams have been strengthened and new collaborations have formed across Australian universities and medical research institutes.

It is essential that this vital new research capacity is retained and developed further so Australia can continue to make a significant contribution to the international research effort and reduce the impact of dementia.

NNIDR is well positioned to contribute to this objective by enabling new and emerging dementia research leaders, embedding essential long-term, large-scale partnerships, cross-disciplinary and cross-sectoral collaborations, and facilitating international linkages.

IMPLEMENTING THE ROADMAP



NNIDR will play a galvanising role to maximise the return on Australian Government investment by continuously reviewing dementia research priorities, connecting and enabling people, linking programs and coordinating efforts toward improving the lives of people with dementia, their carers and families.

References

1. Commonwealth of Australia. (2018) Australia's Boosting Dementia Research Initiative: Report on Early Outcomes. <https://www.nnidr.gov.au/news-centre/publications>
2. Dementia Australia. Types of dementia. <https://www.dementia.org.au/information/about-dementia/types-of-dementia>
3. Livingston G, Sommerlad A, Vasiliki O and Costafreda S. Dementia prevention, intervention and care. The Lancet Commissions (2017), 390(10113):2673-734.
4. Smith K, Flicker L, Lautenschlager N et al. High prevalence of dementia and cognitive impairment in Indigenous Australians. Neurology (2008), 71:1470-1473.
5. Radford K, Mack HA et al, and Broe GA. Prevalence of dementia in urban and regional Aboriginal Australians. Alzheimer's Dement. (2015), 11(3):271-9.
6. Holtzman D and Corriveau R. ADRD Summit 2016 Report to the National Advisory Neurological Disorders and Stroke Council (2016). 6.