

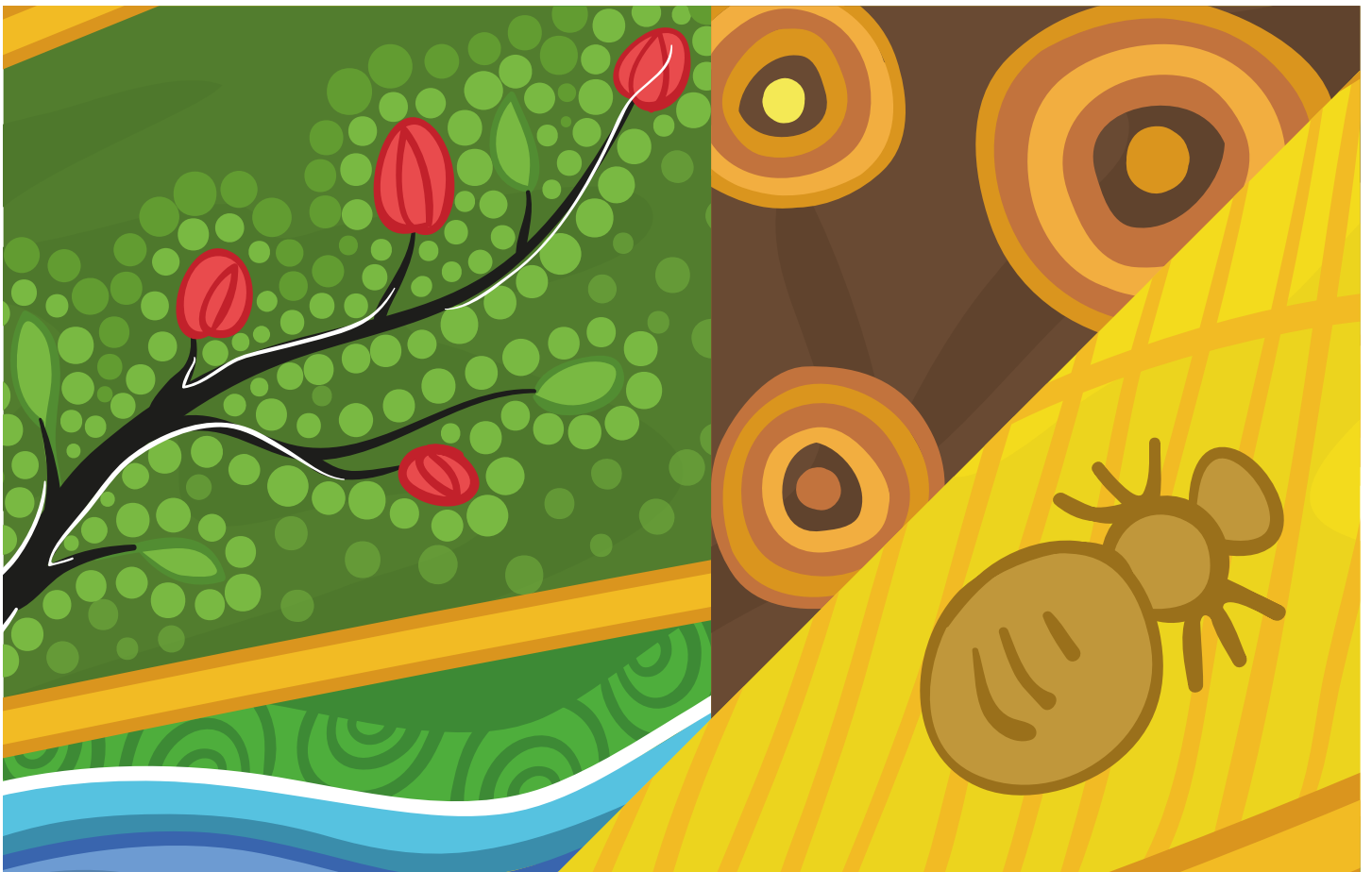


Australian Government

NHMRC National Institute for Dementia Research

# ABORIGINAL AND TORRES STRAIT ISLANDER ROADMAP FOR DEMENTIA RESEARCH AND TRANSLATION

Accelerating research. Enhancing collaboration. Creating change.



# VISION

The improved health and wellbeing of Aboriginal and Torres Strait Islander people at risk of developing or living with dementia, together with their carers, families and communities.

This vision will be achieved through high quality, strengths-based research that values Aboriginal and Torres Strait Islander knowledge systems and community priorities, and recognises the social and cultural determinants of health.

## Purpose

The Aboriginal and Torres Strait Islander Roadmap for Dementia Research and Translation provides guidance to government, researchers, industry and philanthropy on Australia's dementia research strategy and activity in Aboriginal and Torres Strait Islander communities over the longer term. It is a companion document to the 2019 Strategic Roadmap for Dementia Research and Translation, recognising the differing priorities and guiding principles required to address the challenges of dementia in these communities. As well as articulating into the 2019 Strategic Roadmap, it aligns with NHMRC's Road Map 3<sup>1</sup>, and the Australian Government's Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan<sup>2</sup>. The Roadmap will guide the work of the NHMRC National Institute for Dementia Research (NNIDR) and the broader dementia research sector.

## The challenge

Dementia is experienced by Aboriginal and Torres Strait Islander Australians at a much higher rate and with an earlier onset than in non-Indigenous Australians.<sup>3,4</sup> Research indicates that this difference may be accounted for by the higher rates of cardiovascular and metabolic disease, stroke, adverse early life events, lower levels of education and skilled employment, frailty, and brain injury present within Aboriginal and Torres Strait Islander communities.<sup>5</sup> However, there is a relative lack of research targeting dementia and dementia risk in Aboriginal and Torres Strait Islander peoples directly,<sup>6,7</sup> poor recognition of the disease within communities, and a general lack of understanding of the impact of underlying social and cultural determinants by non-Indigenous health care workers and service providers.<sup>8</sup>

## Guiding principles for dementia research

### 1. Maintain a research focus on Aboriginal and Torres Strait Islander community driven priorities

We will guide research investment to meet the research priorities identified by Aboriginal and Torres Strait Islander communities (outlined below) to deliver optimised ageing outcomes for Aboriginal and Torres Strait Islander peoples, including for people living with dementia and their carers and communities.

### 2. Deliver strengths-based and healing-centred research

We will encourage a strengths-based and healing-centred approach to research that focuses on the strengths of Aboriginal and Torres Strait Islander peoples as opposed to a focus on the 'deficits', which is disempowering with the tendency to reinforce negative stereotypes. Strengths-based approaches recognise 'assets' such as knowledge, skills, networks, extended family and cultural identity.<sup>9</sup> Strengths-based and healing-centred research takes a holistic approach that is inclusive of culture, family and community, and ultimately looks toward collective as well as individual healing.

### 3. Build the capacity of Aboriginal and Torres Strait Islander researchers and communities in dementia research

We will support Aboriginal and Torres Strait Islander early career researchers to build their careers in dementia research. We will encourage Aboriginal and Torres Strait Islander health and aged care professionals, students, and personal care assistants to participate, apply for and be funded in research projects.

We will encourage the engagement of Aboriginal and Torres Strait Islander communities, carers and community controlled health and aged care services in all stages of dementia research to ensure that the research is culturally-centred and relevant to Aboriginal and Torres Strait Islander peoples and communities affected by dementia, and to build community research and dementia care capacity.

### 4. Engage in respectful and collaborative relationships with Aboriginal and Torres Strait Islander communities

We will respect the culture and history of Aboriginal and Torres Strait Islander peoples and recognise the leadership and guiding role of elders, to create long-lasting relationships with Aboriginal and Torres Strait Islander communities.

### 5. Build collaboration and partnerships between national and international researchers, service providers and Aboriginal and Torres Strait Islander communities

We will support collaboration and the development of partnerships across Aboriginal and Torres Strait Islander dementia research teams, international researchers, service providers and Aboriginal and Torres Strait Islander communities, to strengthen communication, maximise effort and money invested in research, and produce research results that benefit end users.

### 6. Value Aboriginal and Torres Strait Islander knowledge systems

We recognise that Aboriginal and Torres Strait Islander knowledge systems — a cumulative body of traditional practices, culture, values and laws — will offer insights and ways of doing research that align with and respond to the needs of Aboriginal and Torres Strait Islander people living with dementia, their families and communities, and will benefit dementia research more broadly.

### 7. Acknowledge Data Sovereignty

We will acknowledge the right of Aboriginal and Torres Strait Islander peoples to govern the creation, collection, ownership and application of Indigenous data — that is, information in any format or medium that is about Aboriginal and Torres Strait Islander people collectively and individually.

### 8. Plan and translate research that is realistic, deliverable and addresses community needs

We will prioritise the planning and translation of research that will make a difference to Aboriginal and Torres Strait Islander peoples and communities — that is, research that meets identified community needs and can be readily adapted and implemented across diverse Aboriginal and Torres Strait Islander communities.

### 9. Incorporate a life-course approach to dementia research,<sup>10</sup> taking into account social and cultural determinants of health<sup>11</sup>

We acknowledge that the factors contributing to the risk of dementia are multiple and complex and extend across the lifespan,<sup>12</sup> even though the signs and symptoms of dementia typically only emerge in later life. The development and maintenance of cognitive and brain health (e.g. 'reserve') across the lifespan, and across generations, is important for reducing the burden of dementia in Aboriginal and Torres Strait Islander communities. Adopting a life-course approach<sup>10</sup> to dementia research that takes into account the social, political and cultural determinants of health<sup>11</sup> may lead to increased longevity as well as a delay in the onset of dementia in Aboriginal and Torres Strait Islander people. This approach is also consistent with person-centred, family-centred and culturally responsive care, contributing to better dementia care outcomes.

## Research Priorities 2019–2029

### Priority A: Health literacy

In some Aboriginal and Torres Strait Islander communities, people do not understand how dementia develops, or what to do about it. Health literacy is essential to raising awareness and understanding about dementia and promoting dignity, self-worth and respect for elders with dementia.

The dementia research sector will:

- Determine validated methods to enhance greater awareness and understanding across Aboriginal and Torres Strait Islander communities about dementia.
- Provide evidence that the methods and materials developed are able to be translated into dementia workshops and training for Aboriginal and Torres Strait Islander communities, service providers and health care professionals for implementation Australia wide.

### Priority B: Prevention, risk reduction and diagnosis

There is a relative lack of research targeting dementia in Aboriginal and Torres Strait Islander peoples directly, and poor recognition of the disease within communities, among health care workers and among service providers. This has major implications for the provision of timely and culturally appropriate risk reduction and prevention strategies and diagnosis that incorporate traditional knowledge and practices for Aboriginal and Torres Strait Islander Australians.

The dementia research sector will:

- promote the incorporation of culturally appropriate assessment tools in policy and practice to support timely diagnosis of dementia in Aboriginal and Torres Strait Islander people
- develop guidelines to assist health service providers in supporting and advising Aboriginal and Torres Strait Islander people who are at risk of, or have symptoms of, cognitive decline
- identify protective factors for dementia in Aboriginal and Torres Strait Islander people, including the role of traditional diet, cultural activities, and social/cultural impacts
- develop and evaluate culturally responsive programs, interventions and policies to reduce dementia risk factors and prevent or delay the onset of cognitive decline and dementia.

### Priority C: Access to services and supports

Aboriginal and Torres Strait Islander people with dementia, their families and carers often have difficulties accessing evidence-based health and aged care services, which can result in delayed diagnosis and lack of support. Health services may not have evidence-based dementia protocols and guidelines required to address the health needs of this population. Aboriginal and Torres Strait Islander people with dementia and their carers may not be able to navigate the aged care system to access the supports and services that they require. Individuals and their carers may not feel comfortable accessing and attending mainstream aged care supports and services.

The dementia research sector will:

- develop culturally appropriate evidence-based dementia protocols and guidelines
- identify clear pathways supporting the uptake of dementia protocols and guidelines in health and aged care services
- identify the barriers to Aboriginal and Torres Strait Islander people's access to support services and determine ways to overcome these barriers
- develop and assess models for improving coordination between the health and social care systems.

#### **Priority D: Culturally informed services and workforce**

Families and carers of Aboriginal and Torres Strait Islander people with dementia need improved access to culturally informed information, training, community services and other clinical and emotional supports to meet the changing needs that occur with disease progression. It is also important that the health and wellbeing of families and carers is recognised and supported to enable ongoing care in the home. Survivors of the Stolen Generation have unique wellbeing needs requiring trauma informed approaches to care. Many mainstream health and aged care services want better information and support to work effectively and in a culturally responsive way with Aboriginal and Torres Strait Islander people living with dementia, their families and carers.

Building the workforce capacity of Aboriginal and Torres Strait Islander people in all aspects of the aged care sector — managers, board members and administrators — and in the dementia research field will help create culturally responsive supports, services and interventions for Aboriginal and Torres Strait Islander people living with dementia.

The dementia research sector will:

- develop evidence-based wellbeing and quality of life assessment and resources for health and aged care informed by Aboriginal and Torres Strait Islander values and practices
- develop evidence-based frameworks to ensure cultural security and safety of aged care services for Aboriginal and Torres Strait Islander people with dementia
- identify culturally informed approaches to build the workforce capacity of Aboriginal and Torres Strait Islander people in all aspects of the aged care workforce
- promote initiatives that strengthen the Aboriginal and Torres Strait Islander dementia research workforce.
- Support modification of grant guidelines to facilitate:
  - > the incorporation of Aboriginal and Torres Strait Islander knowledge systems and research methodologies/approaches
  - > engagement with Aboriginal and Torres Strait Islander communities through the research project lifecycle.

#### **Priority E: End of life care**

Aboriginal and Torres Strait Islander communities want culturally responsive services to support Aboriginal and Torres Strait Islander people who want to return to Country and/or their community towards the end of their life. End of life research looking at how best to provide culturally responsive support to Aboriginal and Torres Strait Islander people with dementia and their families to enable this to happen is needed. This includes health economics research into the costs and benefits of providing end of life care services on Country. To enable Aboriginal and Torres Strait Islander people living with dementia to stay on Country and/or within their community for end of life care, it is critical that families and carers have the skills, support and resources they need to provide this care.

The dementia research sector will:

- develop an evidence-based best practice approach to support Aboriginal and Torres Strait Islander people living with dementia and their families to develop and manage a culturally safe plan for end of life including advanced care planning
- undertake economic modelling of provision of end of life care on Country
- identify effective tools and resources to support families and carers to provide end of life care in community/on Country.

## References

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9. [www.lowitja.org.au/sites/default/files/docs/deficit-discourse-strengths-based.pdf](http://www.lowitja.org.au/sites/default/files/docs/deficit-discourse-strengths-based.pdf)
10. The World Health Organization states that the life-course approach "aims at increasing the effectiveness of interventions throughout a person's life. It focuses on a healthy start to life and targets the needs of people at critical periods throughout their lifetime. It promotes timely investments with a high rate of return for public health and the economy by addressing the causes, not the consequences, of ill health." <http://www.euro.who.int/en/health-topics/Life-stages>
11. The World Health Organization defines the social determinants of health as follows, "The social determinants of health (SDH) are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems." [http://www.who.int/social\\_determinants/en/](http://www.who.int/social_determinants/en/)
12. Arkles, R., Jackson Pulver, L., et al. (2010). *Ageing, Cognition and Dementia in Australian Aboriginal and Torres Strait Islander Peoples*. Sydney: Neuroscience Research Australia & Muru Marri Indigenous Health Unit, UNSW. [Commissioned by DCRC]