



Aboriginal and Torres Strait Islander Action Plan for Dementia Research and Translation

*Linked to Aboriginal and Torres Strait Islander Roadmap
for Dementia Research and Translation*

Vision

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

Introduction

The Aboriginal and Torres Strait Islander Roadmap for Dementia Research and Translation sets out current dementia research and translation priorities for Aboriginal and Torres Strait Islander communities. The Roadmap will guide the work of the NHMRC National Institute for Dementia Research (NNIDR) and the broader dementia research sector. This Action Plan outlines actions against each of the five priorities in the Roadmap, to be undertaken by the dementia research sector:

- **Priority A:** Health literacy
- **Priority B:** Prevention, risk reduction and diagnosis
- **Priority C:** Access to services and supports
- **Priority D:** Culturally informed services and workforce
- **Priority E:** End of life care

This Action Plan aims to achieve a reduction in the current gap between dementia incidence, prevalence and health and wellbeing outcomes for Aboriginal and Torres Strait Islander peoples. Progress towards implementing this Action Plan will be reviewed every year by NNIDR on advice from NHMRC Principal Committee Indigenous Caucus (PCIC).

Actions to implement the Aboriginal and Torres Strait Islander Roadmap for Dementia Research and Translation

Priority A: Health literacy

1	Fund community-led research to develop validated methods to enhance dementia awareness and understanding and provide evidence that these methods and materials are translatable
2	Fund innovative research partnership models with Aboriginal and Torres Strait Islander communities and community controlled organisations
3	Build capacity, empower and enhance the health and wellbeing of Aboriginal and Torres Strait Islander peoples at-risk of or living with dementia, their carers, families, communities and service providers through dementia workshops and training
4	Facilitate and build partnerships between the Aboriginal community, service organisations and dementia researchers to enable the translation and delivery of research outcomes

What does success look like?

- A marked increase in dementia awareness and understanding, including potentially modifiable lifestyle factors, in Aboriginal and Torres Strait Islander peoples, communities, organisations, health and aged care professionals

We will measure this by:

- Development and implementation of evidence-based sustainable tools, methods and resources
- Delivery of capacity building dementia workshops and training schemes with strong engagement and participation of Aboriginal and Torres Strait Islander peoples and communities
- An increase in new and existing national partnerships and collaborations that are funded to drive research translation and implementation

Priority B: Prevention, risk reduction and diagnosis

5	Fund community-led research to identify protective factors and develop and evaluate culturally responsive programs, interventions, new and enabling technologies, and policies
6	Develop evidence-based guidelines to assist mainstream and Aboriginal and Torres Strait Islander controlled health service organisations in supporting and advising Aboriginal and Torres Strait Islander peoples at risk of, or experiencing, cognitive decline

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Incorporate culturally appropriate assessment tools into policy and practice

What does success look like?

- Development of timely and culturally appropriate risk reduction and prevention strategies and diagnosis
- Reduction in time taken to achieve dementia diagnosis for Aboriginal and Torres Strait Islander peoples

We will measure this by:

- Development of new and effective assessment tools to improve diagnosis, prevention and care
- Implementation of evidence-based guidelines to support and advise Aboriginal and Torres Strait Islander peoples
- Creation and implementation of culturally responsive prevention and risk reduction programs
- Identification of risk factors leading to cognitive decline and dementia in Aboriginal and Torres Strait Islander communities

Priority C: Access to services and supports

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Fund research that aims to develop culturally appropriate evidence-based dementia protocols and guidelines

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Support partnerships that drive the uptake of Aboriginal and Torres Strait Islander dementia protocols and guidelines in health and aged care services

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Fund roundtables and workshops that seek to identify enablers and barriers to Aboriginal and Torres Strait Islander peoples' access to support services, and improve coordination between the health and aged care systems

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Fund the development and evaluation of models, effective tools and resources that support families, carers and community controlled organisations to provide dementia care in community / on Country

What does success look like?

- Improved best practice dementia care, support and services that are easily accessible for Aboriginal and Torres Strait Islander peoples living with dementia, and their families, carers and communities
- Effective dementia care support and services in community / on Country for Aboriginal and Torres Strait Islander peoples

We will measure this by:

- Development of sustainable collaborations and partnerships between Aboriginal and Torres Strait Islander communities, researchers, supports and services

- Development and implementation of dementia care support and services in community / on Country

Priority D: Culturally informed services and workforce

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Support the development of evidence-based wellbeing and quality of life tools and resources

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Support the development of evidence-based frameworks to ensure cultural security and safety and to empower, build capacity and increase the number of Aboriginal and Torres Strait Islander peoples working in the aged care system

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Identify culturally informed models of care developed with families, communities and carers of Aboriginal and Torres Strait Islander peoples with dementia, encompassing:

- Traditional healing practices
- Home-based supports and respite
- Clinical, social and emotional wellbeing supports
- Education and training

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Fund initiatives that strengthen the Aboriginal and Torres Strait Islander dementia research workforce, including:

- NHMRC scholarships for Aboriginal and Torres Strait Islander undergraduate, graduate and post graduate students to pursue a career in dementia research
- support schemes that provide salary and research funding to Australia's leading Aboriginal and Torres Strait Islander dementia researchers
- enhanced NNIDR leadership program with an integrated approach to foster and mentor emerging Aboriginal and Torres Strait Islander leaders in dementia research
- opportunities to increase the number of Aboriginal and Torres Strait Islander peoples as Principal Investigators in dementia research projects
- capacity building in research methods for community-based researchers who have developed research expertise from non-traditional pathways (via research institutions)

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Ensure NNIDR business cases for advancing this Roadmap, as outlined in the NHMRC Indigenous Research Excellence Criteria, facilitate:

- the incorporation of Aboriginal and Torres Strait Islander knowledge systems and research methodologies/approaches in research projects
- engagement with Aboriginal and Torres Strait Islander communities through the research project lifecycle and in making decisions on future data use

What does success look like?

- Cultural healing approaches are incorporated in aged care policy and practice resulting in improved quality of life for Aboriginal and Torres Strait Islander peoples living with dementia, their families and carers
- Better understanding of and capacity to respond to carer wellbeing and support needs
- A strengthened Aboriginal and Torres Strait Islander aged care and dementia research workforce

We will measure this by:

- Recommended funding schemes in place
- The development and implementation of evidence-based, culturally informed wellbeing and quality of life frameworks, tools and resources
- The development and implementation of evidence-based, culturally informed models of care for Aboriginal and Torres Strait Islander dementia carers
- The development and implementation of evidence-based frameworks for the Aboriginal and Torres Strait Islander dementia aged care workforce
- NNIDR business cases support the incorporation of Aboriginal and Torres Strait Islander knowledge systems and lifecycle engagement

Priority E: End of life care

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Fund research to develop and manage an evidence-based, culturally safe, best practice approach for end of life care for Aboriginal and Torres Strait Islander peoples living with dementia, including advanced care planning

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Fund research that aims to identify cost-effectiveness of the provision of dementia care and end of life care in community / on Country assisted by the community, community controlled organisations and/or culturally centred support services

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Fund the development of effective tools and resources that support families, communities and carers to provide end of life care in community / on Country

What does success look like?

- Aboriginal and Torres Strait Islander peoples with dementia are enabled to live on Country or in their community for end-of-life care, assisted by the community and culturally centred support services
- Improved quality of life and support for a culturally safe, comfortable and dignified passing

We will measure this by:

- Implementation and evaluation of evidence-based culturally appropriate palliative care pathways to support quality of end of life care
- Implementation of culturally centred palliative care that is available in all care settings to all Aboriginal and Torres Strait Islander people living with dementia and their families