



Australian Government

NHMRC National Institute for Dementia Research

COMMUNITY CONSULTATION REPORT: DEVELOPMENT OF AN ABORIGINAL AND TORRES STRAIT ISLANDER STRATEGIC ROADMAP FOR DEMENTIA RESEARCH AND TRANSLATION 2019

Accelerating research. Enhancing collaboration. Creating change.



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BACKGROUND TO THE ROADMAP

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.^{1,2} 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.³ However, there is a relative lack of research targeting dementia and dementia risk in Aboriginal and Torres Strait Islander peoples directly,⁴ 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.⁵

The above factors have had major implications for the provision of timely and culturally appropriate health services for Aboriginal and Torres Strait Islander Australians. Further, not addressing these factors, fails to adequately meet one of the goals in the National Aboriginal and Torres Strait Islander Health Plan (NATSHP) 2013-2023, “Older Aboriginal and Torres Strait Islander people are able to live out their lives as active, healthy, culturally secure and comfortably as possible.”⁶

The NHMRC National Institute for Dementia Research (NNIDR) worked with NHMRC’s Principal Committee Indigenous Caucus and the Centre for Aboriginal Medical and Dental Health (CAMDH) at the University of Western Australia to establish a Working Group (see Appendix A). This Working Group was comprised of a majority of Aboriginal and Torres Strait Islander members. Its purpose was to consider ways to address identified community needs. The Working Group recommended that stakeholders be brought together to advise on a consultation process that will lead to the development of an Aboriginal and Torres Strait Islander Dementia Research Roadmap.

Steps in developing the Aboriginal and Torres Strait Islander Strategic Roadmap for Dementia Research and Translation include:

1. **A Round Table Meeting** (6 June 2018) to foster collaboration between researchers, clinicians and community representatives involved with dementia and Aboriginal and Torres Strait Islander health and to begin the development of the roadmap including: outlining roadmap objectives, identifying key research priorities, and translation of these to policy and practice initiatives
2. **Community consultations and call for written submissions** (August to mid-October) to inform the Roadmap on Aboriginal and Torres Strait Islander community priorities for Aboriginal and Torres Strait Islander dementia research (see Appendix B)
3. **Writing of the draft roadmap** (October 2018).
4. **Aboriginal and Torres Strait Islander Ageing Advisory Group (ATSIAAG) presentation and discussion forum** (20 November 2018) to present draft roadmap and receive feedback.
5. **Consideration by NHMRC Principal Committee Indigenous Caucus** (February 2019)
6. **Development of Action Plan** (early-mid 2019).
7. **Implementation**

¹ Smith K, Flicker L, Lautenschlager N *et al.* High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology* 2008; 71: 1470–1473.

² Radford K, Mack HA, *et al.*, and Broe GA. Prevalence of dementia in urban and regional Aboriginal Australians. *Alzheimers Dement.* (2015), 11(3):271-9.

³ Smith K, Flicker L, *et al.*, and LoGiudice D. Factors Associated with Dementia in Aboriginal Australians. *Aust N Z J Psychiatry* (2010) 44: 888-893

⁵ LoGiudice D, Smith K, *et al.*, and Flicker L. Incidence and predictors of cognitive impairment and dementia in Aboriginal Australians: A follow up study of 5 years. *Alzheimer’s & Dementia*, 2015 Mar; 12:252-261

⁶ Radford, K., Lavrencic, L. M., Delbaere, K., Draper, B., Cumming, R., Daylight, G., Broe, G. A. (2018). Factors associated with the high prevalence of dementia in older Aboriginal Australians. *Journal of Alzheimer Disease*, DOI: 10.3233/JAD-180573.

⁴ AIHW; Aboriginal and Torres Strait Islander Health Performance Framework 2012: detailed Analyses.

⁵ Lindeman MA, Smith K, *et al.*, Community care for Indigenous older people: An update. *Australas J Ageing.* (2016) doi:10.1111/ajag.12316.

⁶ <http://www.health.gov.au/natsihp>: 38

COMMUNITY CONSULTATION PROCESS

Background to the consultation process

On 6 June 2018, researchers, service providers and Aboriginal and Torres Strait Islander community representatives came together for a Round Table Meeting to discuss the current needs of Aboriginal and Torres Strait Islander peoples living with dementia, and the needs of their carers, families and communities (see Appendix A for a list of participants). Participants engaged in lengthy discussions regarding the priorities and objectives of an Aboriginal and Torres Strait Islander Strategic Roadmap for Dementia Research, as well as the current issues Aboriginal and Torres Strait Islander peoples face during their dementia journey relating to care, support and service provision.

Round Table participants agreed on the value of a broad-based consultation process and identified priorities for action across four broad themes:

- Building collaboration across Aboriginal and Torres Strait Islander dementia research teams
- Building the Aboriginal and Torres Strait Islander dementia research workforce
- Engaging respectfully and effectively with Aboriginal and Torres Strait Islander communities
- High priority Aboriginal and Torres Strait Islanders dementia research areas.

Community Consultation process

The Roadmap Working Group (see Attachment B) took a two-pronged approach to consultation:

A call for written submissions (August – mid-October 2018)

The Working Group sought broad ranging input on the ideas that were discussed at the Round Table Meeting and developed three sets of questions for people living with dementia, their carers and families, service providers, and researchers (see Appendix C for the three sets of questions). The call for written submissions was promoted on the NNIDR website and through NNIDR and Working Group members’ networks.

A total of 89 online submissions were received, with responses from all states and territories except Tasmania. Of those responses, 44 were from service providers, 16 from researchers, and 29 from Aboriginal and Torres Strait Islander community members. A total of 40 responses were from people in major cities, 29 from people in regional areas, seven from people in rural areas and 15 from people in remote communities.

Queensland	19
New South Wales	41
Western Australia	8
Northern Territory	3
Victoria	15
South Australia	2
Tasmania	0
Australian Capital Territory	3

Table 1: Breakdown of written responses by state/territory

Face-to-face community consultations (August – mid-October 2018)

Community consultations were held in urban, regional and remote Aboriginal and Torres Strait Islander communities across the country. A total of **253** community members including Aboriginal and Torres Strait Islander peoples living with dementia, their carers and families, community support workers and community health workers, and aged care service providers and aged care researchers participated in the consultations.



Total of **26** locations across Australia

Total of **253** participants

Figure 1: Community consultation locations

Consultations were held in every state in Australia, with a total of **26** consultation locations including urban, rural and remote Aboriginal and Torres Strait Islander communities. Participants were invited to participate through Aboriginal community centres, health and aged care services and research and community services. See Appendix D for a list of consultation facilitators.

At the community consultations participants discussed:

- Community perceptions and understanding of dementia
- Educations and awareness around dementia
- Culturally-centred care
- Family and community supports and services
- Priorities for research, including gaps in current research
- What participants would most like to see changed to improve the lives of Aboriginal and Torres Strait islander peoples living with dementia, their families and communities.

KEY THEMES FROM THE COMMUNITY CONSULTATIONS AND WRITTEN SUBMISSIONS

The Working Group met with the project team on 25 October to analyse the feedback from the consultation process. The Working Group arranged the key themes from the feedback under two headings:

- Guiding principles for dementia research – how research is undertaken
- Dementia research priorities – the areas of research Aboriginal and Torres Strait Islander communities would like dementia researchers to focus on.

Guiding principles for dementia research

1. Maintain a research focus around 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 improved 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.⁷ 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 peoples 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.

⁷ www.lowitja.org.au/sites/default/files/docs/deficit-discourse-strengths-based.pdf

9. Incorporate a life-course approach to dementia research,⁸ taking into account social and cultural determinants of health⁹

We acknowledge that the factors contributing to the risk of dementia are multiple and complex and extend across the lifespan,¹⁰ 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 approach¹¹ to dementia research that takes into account the social, political and cultural determinants of health¹² may lead to increased longevity as well as a delay in the onset of dementia in Aboriginal and Torres Strait Islander peoples. This approach is also consistent with person-centred, family-centred and culturally responsive care, contributing to better dementia care outcomes.

Dementia research priorities

Health literacy and awareness for dementia and respect for elders with dementia in Aboriginal and Torres Strait Islander communities, and health and aged care services

Health literacy is important for people because it influences their capacity to make informed decisions and to manage their health and health care. Poor health literacy results in poorer health outcomes. Health literacy is also important for health care providers because it shapes how they manage their relationships with the people to whom they provide care and how they deliver health care. For Aboriginal and Torres Strait Islander communities, health literacy is important at the family, carer, community and individual level to empower, build capacity and support family-centred decision-making.

In some Aboriginal and Torres Strait Islander communities, people do not understand how dementia develops, or what to do about it. Some people may see it as a normal part of getting older and think that nothing can be done. There may be no words to describe dementia in traditional languages. Others may feel shame or think that the symptoms are part of 'pay back' for doing something wrong. People living with dementia, their carers and families described their experiences as upsetting, isolating and traumatic making them feel lonely, angry, frustrated and sad. Health literacy is essential to raising awareness and understanding about dementia and promoting dignity and self-worth.

Dementia prevention, risk reduction and diagnosis, including traditional knowledge and practices

There is a relative lack of research targeting dementia in Aboriginal and Torres Strait Islander peoples directly¹³ and poor recognition of the disease within communities, among health care workers and among service providers.¹⁴ These factors have had major implications for the provision of timely and culturally appropriate risk reduction and prevention strategies and diagnosis that incorporates traditional knowledge and practices for Aboriginal and Torres Strait Islander Australians.

More education and training is needed on dementia prevention for Aboriginal and Torres Strait Islander communities, health professionals and service providers. A better understanding of the modifiable risk factors for dementia in Aboriginal and Torres Strait Islander peoples is also required, with development and evaluation of culturally responsive interventions to reduce dementia risk factors, and prevent or delay cognitive decline and dementia onset.

Accurate diagnosis underpins appropriate treatment and care. We must optimise timely detection and management of cognitive impairment and dementia within Aboriginal and Torres Strait Islander communities.

⁸ 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>

⁹ 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/

¹⁰ 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]

¹¹ 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>

¹² 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/

¹³ AIHW; Aboriginal and Torres Strait Islander Health Performance Framework 2012: detailed Analyses.

¹⁴ Lindeman MA, Smith K, et al., Community care for Indigenous older people: An update. *Australas J Ageing*. (2016) doi:10.111/ajag.12316.

Improve access to evidence-based health and aged care services and supports for Aboriginal and Torres Strait Islander peoples with dementia, their families and their carers

Aboriginal and Torres Strait Islander peoples 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 peoples 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.

Research is needed to inform health and aged care services and supports for Aboriginal and Torres Strait Islander peoples. This includes development of culturally appropriate dementia protocols and guidelines, and models for improving coordination between the health and social care systems. Evaluation of existing formal and informal care approaches and infrastructure in Aboriginal and Torres Strait Islander communities is also needed with a focus on how to increase the number of Aboriginal and Torres Strait Islander controlled organisations providing aged care services to Aboriginal and Torres Strait Islander peoples living with dementia, and their families and carers. Research to identify the barriers to Aboriginal and Torres Strait Islander peoples accessing support services and ways to overcome those barriers is critical.

Culturally informed service provision and workforce that promotes healing, wellbeing and quality of life for Aboriginal and Torres Strait Islander peoples with dementia, their families and carers.

Families and carers of Aboriginal and Torres Strait Islander peoples 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. 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 peoples living with dementia, their families and carers.

The creation and evaluation of equitable, culturally-sensitive service delivery models that aim to relieve the distress and pain experienced by Aboriginal and Torres Strait Islander peoples living with dementia and promote healing and wellbeing across the disease course is essential for good health outcomes.

Building the workforce capacity of Aboriginal and Torres Strait Islander peoples in all aspects of the aged care workforce – from personal care assistants through to 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 peoples living with dementia.

We need an increase in research opportunities to investigate, enhance and maintain the overall wellbeing and quality of life of Aboriginal and Torres Strait Islander peoples with dementia including healing and trauma informed approaches to care. Research that enables Aboriginal and Torres Strait Islander peoples to stay on Country and/or in their community to maximise quality of life, wellbeing and healing is essential for strengthening and keeping families together.

End of life care for Aboriginal and Torres Strait Islander peoples with dementia and their carers

Aboriginal and Torres Strait Islander communities want culturally responsive services to support Aboriginal and Torres Strait Islander peoples who want to return to Country and/or their community towards the end of their life to be able to do so. End of life research looking at how best to provide culturally responsive support to Aboriginal and Torres Strait Islander peoples 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 peoples 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.

APPENDIX A: ROUND TABLE MEETING SUMMARY: 6 JUNE 2018 - PARTICIPANTS

- Sandra Eades
 - Janice Besch
 - Dawn Bessarab
 - Kate Smith
 - Terry Donovan
 - Roslyn Malay
 - Venessa Curnow
 - Kylie Radford
 - Dina LoGiudice
 - Laurie Yambo
 - Bojana Kos
 - Jo Hughson
 - Wendy Allan
 - Tony Broe
 - Laurie Yambo
 - Robert Sanson-Fisher
 - Maree McCabe
 - Eddy Strivens
 - Gail Daylight
 - Shayne Bellingham
 - Alison Nelson
 - Lianne Gilchrist
 - Graham Aitken
 - Kelly Reynolds
 - University of Melbourne and PCIC
 - Dementia Australia
 - University of Western Australia
 - University of Western Australia
 - NeuRA
 - University of Western Australia
 - Queensland Health
 - NeuRA and University of New South Wales
 - University of Melbourne
 - Derby Aboriginal Health Service
 - Dementia Australia
 - University of Melbourne
 - NeuRA
 - NeuRA
 - Derby Aboriginal Health Services
 - University of Newcastle
 - Dementia Australia
 - Queensland Health
 - NeuRA
 - Lowitja
 - Institute for Urban Indigenous Health
 - University of Western Australia
 - Aboriginal Community Care SA
 - University of Western Australia
- Build a NNIDR Aboriginal and Torres Strait Islander dementia advisory group

APPENDIX B: ROADMAP WORKING GROUP

- Kate Smith (Co-Chair) University of Western Australia
- Dawn Bessarab (Co-Chair) University of Western Australia
- Sandra Eades University of Melbourne and PCIC
- Janice Besch NHMRC National Institute for Dementia Research
- Lianne Gilchrist University of Western Australia
- Roslyn Malay University of Western Australia
- Venessa Curnow Queensland Health
- Kylie Radford NeuRA and University of New South Wales
- Dina LoGiudice University of Melbourne and Melbourne Health
- Kelly Reynolds University of Western Australia
- Lynette Goldberg University of Tasmania/Wicking Dementia Research and Education Centre

APPENDIX C: CALL FOR WRITTEN SUBMISSIONS – QUESTIONS

CONSULTATION QUESTIONS FOR PEOPLE LIVING WITH DEMENTIA, THEIR FAMILIES AND CARERS

The Working Group wants to find out more about the particular challenges being experienced by Aboriginal and Torres Strait Islander peoples who are living with dementia, and their families and carers.

1. What do you and other Aboriginal and Torres Strait Islander people in your community think and know about dementia? Is the condition well understood?

At our Round Table Meeting, it was reported that in some communities, people don't understand how dementia develops, or what to do about it. There may be no word to describe it in local language. Some people may see it as a normal part of getting older and that nothing can be done about it. Others may feel shame or think that the symptoms are part of 'pay back' for that person. Overall, people with dementia, their carers and families may not know how to access supports and services.

There may be ways to prevent or delay the progression of dementia to lead a longer, healthier life. This can allow cultural knowledge to be protected and passed on. It can also help to keep communities together and ensure that people with dementia, their carers and families are supported in difficult times.

- In your community or experience, can you tell us what it is like for people living with dementia, their families and carers?

[Click or tap here to enter text.](#)

- Can you suggest any ways that could make the biggest difference in raising awareness, understanding and knowledge about how to live with dementia in your community?

[Click or tap here to enter text.](#)

2. Is there any good community support for Aboriginal and Torres Strait Islander peoples with dementia and their families? Can you tell us what is working well?

[Click or tap here to enter text.](#)

3. How do health service providers help in identifying and dealing with dementia or memory issues?

It was reported at the round table meeting, that many medical and aged care services want better information and support to effectively work with Aboriginal and Torres Strait Islander peoples, their families and carers who are living with dementia. The Roadmap will help to ensure that service providers have quality information on best practice dementia advice and care.

- What kind of care support has been valuable to you or your family or community in the past? What did you like about it?

[Click or tap here to enter text.](#)

- What gaps in support or knowledge or understanding have you noticed from service providers, when it comes being supported as a person, family member or carer living with dementia?

[Click or tap here to enter text.](#)

4. What would you most like to see changed? Please rank your ideas in order of priority

[Click or tap here to enter text.](#)

5. What are the gaps in dementia research for Aboriginal and Torres Strait Islander peoples?

Click or tap here to enter text.

CONSULTATION QUESTIONS FOR SERVICE PROVIDERS

The Working Group will also seek advice from communities on what they would like to see identified in the Roadmap:

1. What guiding principles should be observed in the conduct of dementia research in your area of service provision?

The main guiding principles discussed at the Round Table Meeting that should be observed in the conduct of dementia research are listed below;

- Building the capacity of Aboriginal and Torres Strait Islander researchers and communities
- Focus on research that benefits the community
- Research should focus around Aboriginal and Torres Strait Islander community priorities
- Building genuine Aboriginal and Torres Strait Islander community engagement
- Focus on research that is culturally appropriate
- Focus on research that is realistic and feasible

These may differ from principles that should be observed in the conduct of dementia research in your area of service provision and you are encouraged to discuss any specifics from your perspective.

- Do you agree with the above guiding principles discussed at the Round Table Meeting?

Click or tap here to enter text.

- Are there any guiding principles specific to your area of service provision that haven't been listed above?

Click or tap here to enter text.

2. What objective/s do you believe should be established for Aboriginal and Torres Strait Islander Research?

After discussions at our Round Table Meeting we believed our objective for Aboriginal and Torres Strait Islander research should be to improve the health and wellbeing of Aboriginal and Torres Strait Islander peoples with dementia and their carers, through high quality, strength-based research that values Aboriginal and Torres Strait Islander knowledge systems and community priorities.

Some ways in which we believed this could be done was through valuing Aboriginal and Torres Strait Islander values, creating strong community engagement, focusing on strength-based and healing-centered research, funding research that focuses on community driven priorities with early and continual consultation with the Aboriginal and Torres Strait Islander communities and creating a family centered model of research so as to include not only the thoughts and perspectives of the person living with dementia, but their families and communities also.

- Do you agree with the above objective created at the Round Table Meeting?

Click or tap here to enter text.

- What other objectives should be included?

Click or tap here to enter text.

- In your experience, are there any methods you would suggest for implementing this objective?

Click or tap here to enter text.

3. What service provision improvements should we seek to achieve, through research in the

a) Short term?

Click or tap here to enter text.

b) Medium term?

Click or tap here to enter text.

c) Long term?

Click or tap here to enter text.

4. What should be our priorities for action?

Round Table Meeting attendees identified the following priorities for action:

- Greater health literacy/awareness for dementia in Aboriginal and Torres Strait Islander Communities
- Incorporation of cultural knowledge in research projects
- Greater emphasis on prevention, care, support and services available for Aboriginal and Torres Strait Islander peoples living with dementia and their families and communities
- Building stronger relationships between researchers, service providers and Aboriginal and Torres Strait Islander communities
- Building a greater Aboriginal and Torres Strait Islander workforce in dementia research, implementation and service provision

Priorities for research may differ for different communities, and we welcome any specifics from your perspective.

- Do you agree with the above priorities for action? Are there any priorities for action that have not been listed?

Click or tap here to enter text.

- How do you believe we can implement these priorities?

Click or tap here to enter text.

5. What barriers will we need to overcome in achieving these outcomes and addressing these priorities?

Click or tap here to enter text.

6. Who should we work with so as to ensure that our research findings lead to better prevention, diagnosis and care for Aboriginal people and Torres Strait Islanders living with dementia, their families and carers?

Click or tap here to enter text.

CONSULTATION QUESTIONS FOR RESEARCHERS

1. How do we build collaboration across research teams?

The Round Table Meeting discussed the greater need for collaboration between Aboriginal and Torres Strait Islander research teams in order to maximise efficiency in time and money in research, as well as combining research and sharing data to reduce the number of similar projects. After discussions, the following ways to build this collaboration were discussed:

- Building of a formalised Aboriginal and Torres Strait Islander committee to advise the NNIDR
- Building a network or database containing all Aboriginal and Torres Strait Islander dementia projects and research organisations
- Creating structured processes for facilitating collaboration amongst research projects
- Creating partnership funding schemes for collaborations

In your experience, what is needed to build collaboration across research teams?

Click or tap here to enter text.

2. What can we do to increase the number of Aboriginal and Torres Strait Islander peoples choosing dementia research and translation as a career?

Ideas fostered at the Round Table Meeting were centred around mentoring and funding schemes, greater access to education and training for Aboriginal and Torres Strait Islander peoples and encouragement for Aboriginal and Torres Strait Islander health workers, mental health workers and personal care assistants to join research teams or projects.

- Do you have any suggestions on how to attract Aboriginal and Torres Strait Islander peoples to dementia research and translation?

Click or tap here to enter text.

- In your community or experience, can you describe what funding schemes would need to be implemented to support Aboriginal and Torres Strait Islander peoples pursuing a career in dementia research and translation?

Click or tap here to enter text.

3. What principles should be followed in engaging respectfully and effectively with Aboriginal and Torres Strait Islander communities? Are there any dementia-specific protocols that should be observed?

Click or tap here to enter text.

4. What research outcomes should we seek to achieve in the;

a) Short term?

Click or tap here to enter text.

b) Medium term?

Click or tap here to enter text.

c) Long term?

Click or tap here to enter text.

5. What should be our priorities for research?

Round Table Meeting attendees identified the following key research priorities:

- Greater health literacy/awareness for dementia in Aboriginal and Torres Strait Islander Communities
- Implementation of cultural knowledge in research projects
- Research focused around prevention and risk reduction
- Research that focuses on care, support and services available for Aboriginal and Torres Strait Islander peoples living with dementia
- Research that is strength-based and healing-centred
- Life-course approach to research
- Research that is clinically relevant and driven by the communities

Priorities for research may differ for different communities, and we welcome any specifics from your perspective.

- Do you agree with the above priorities for research discussed at the Round Table Meeting?

Click or tap here to enter text.

- Are there any other priorities you believe should be included haven't been listed above?

Click or tap here to enter text.

6. What barriers will we need to overcome in achieving these outcomes and addressing these priorities?

Click or tap here to enter text.

7. Who should we work with so as to ensure that our research findings lead to better prevention, diagnosis and care for Aboriginal people and Torres Strait Islanders living with dementia, their families and carers?

Click or tap here to enter text.

APPENDIX D: COMMUNITY CONSULTATION FACILITATORS

An outline of who led each consultation can be found below:

Location	Facilitators	Facilitator Organisation
• Balga, Perth, WA	• Kate Smith, Kelly Reynolds, Lianne Gilchrist, Lorraine Sholson	• University of Western Australia
• Guildford, Perth, WA	• Lianne Gilchrist, Lorraine Sholson	• University of Western Australia
• Broome, WA	• Roslyn Malay	• University of Western Australia
• Fitzroy Crossing, WA	• Roslyn Malay	• University of Western Australia
• Bidyadanga, WA	• Roslyn Malay	• University of Western Australia
• Kalgoorlie, WA	• Kelly Reynolds, Christianne White	• University of Western Australia
• Darwin, NT	• Susan Williams	• Dementia Australia, NT
• Coconut Grove, NT	• Susan Williams	• Dementia Australia, NT
• Thursday Island, Torres Strait Islands	• Eddy Strivens, Sarah Russell, Rachel Quigley, Betty Sagigi	• Queensland Health & James Cook University
• Warraber Island, Torres Strait Islands	• Eddy Strivens, Sarah Russell, Rachel Quigley, Betty Sagigi	• Queensland Health & James Cook University
• Coconut Island, Torres Strait Islands	• Eddy Strivens, Sarah Russell, Rachel Quigley, Betty Sagigi	• Queensland Health & James Cook University
• Badu Island, Torres Strait Islands	• Eddy Strivens, Sarah Russell, Rachel Quigley, Betty Sagigi	• Queensland Health & James Cook University
• Moa Island, Torres Strait Islands	• Eddy Strivens, Sarah Russell, Rachel Quigley, Betty Sagigi	• Queensland Health & James Cook University
• Gympie, QLD	• Joni Parmenter	• Institute for Urban Indigenous Health (UIIH)
• Harvey Bay, QLD	• Joni Parmenter	• Institute for Urban Indigenous Health (UIIH)
• Nambour, QLD	• Joni Parmenter	• Institute for Urban Indigenous Health (UIIH)
• Morayfield, QLD	• Joni Parmenter	• Institute for Urban Indigenous Health (UIIH)
• Coffs Harbour, NSW	• Terry Donovan, Wendy Allan, Kylie Sullivan	• NeuRA
• Broken Hill, NSW	• Sharon Wall, Lauren Poulos	• NeuRA
• Sydney, NSW	• Sharon Wall, Lauren Poulos	• NeuRA
• Ballarat, VIC	• Kate Bradley	• University of Melbourne & Melbourne Health

- Brunswick, Melbourne, VIC
- Reservoir, Melbourne, VIC
- Circular Head, TAS
- Christies Beach, SA
- Adelaide, SA
- Dina LoGiudice, Mary Belfrage
- Kate Bradley, Harry Douglas
- Dianne Baldock
- Mark Elliott, Ivan Copley
- Mark Elliott, Ivan Copley
- University of Melbourne & Melbourne Health
- University of Melbourne & Melbourne Health
- Circular Head Aboriginal Corporation
- Mark Elliott Consulting
- Mark Elliott Consulting