

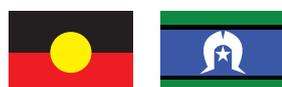
# Working with older Aboriginal and Torres Strait Islander people

This Briefing presents evidence from research to guide mainstream community aged care organisations and practitioners on working in a respectful and culturally sensitive manner with Aboriginal and Torres Strait Islander people. It aims to help enhance the quality of care by ensuring it is underpinned by reflection, knowledge, understanding and respect. However, this Briefing should not be understood as a universal set of protocols, nor as a prescription for care, as Aboriginal and Torres Strait Islander cultures are complex and extremely diverse, and accepted protocols vary across communities.

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## Research to Practice Briefings

The Benevolent Society's series of Research to Practice Briefings bring together lessons from the literature on topical issues in community aged care as a resource for those working in this sector. As in most areas of social policy and practice, the research evidence on community care is continually evolving. The Briefings aim to distil key themes and messages from the research and to point to promising and innovative practices. An advisory group of academics and expert practitioners provide advice and peer review.



This Briefing was prepared by Sharon Wall and the Koori Growing Old Well Study Project Team at Neuroscience Research Australia, in partnership with The Benevolent Society. Its preparation was informed by extensive community participation and consultation with Aboriginal communities undertaken by the Koori Growing Old Well Study Project Team. Full details of the consultation and participation undertaken are available on The Benevolent Society's website.

We acknowledge with thanks the NSW Aboriginal Community Care Gathering Committee, which generously provided advice, shared cultural knowledge and permitted the use of excerpts from their Policy Position.

*There are many common stereotypes of Aboriginal peoples. One is that we are all the same and conform to the idealised image of the naked Aborigine standing with a spear in hand watching the sun set. This is a picture which quickly dissolved into the reality of the 21st century. We are as different as the landscapes of the coast, desert, rainforest and snowy mountains. The land is different and so are we, the first peoples of the land.*

Dr Irene Watson, Aboriginal lawyer, writer and activist

### History and culture

Australia has two Indigenous cultures as part of its national heritage – Aboriginal, and Torres Strait Islander. Aboriginal<sup>1</sup> and Torres Strait Islander peoples are the First Australians, having lived in Australia for more than 40,000 years. There is no place in Australia that is not Aboriginal or Torres Strait Islander land.

Culture is of central importance to how Aboriginal and Torres Strait Islander peoples understand their identities and live their lives. Through culture, Aboriginal and Torres Strait Islander peoples experience strong connections to family, country, spirituality and community. However, these cultures are complex and extremely diverse. There is no single Aboriginal and Torres Strait Islander culture or group, but numerous groupings, languages and kinships, and diverse ways of living. Aboriginal and Torres Strait Islander peoples may live in urban, rural or remote settings, in urbanised, traditional or other lifestyles, and may move between these ways of living. As in all cultures, individuals are influenced by their own experiences and their own stories.

### Relationships

The system of kinship, which determines an Aboriginal or Torres Strait Islander person's extended family and land, is central to community. Kinship defines where a person fits into their community and what rights and responsibilities each person has within that community. The roles

and systems of families may vary between each Aboriginal or Torres Strait Islander community but all serve a similar function.

*Older people are an integral part of the social fabric of Aboriginal and Torres Strait Islander communities. Social fabric is what makes a community interesting, meaningful and purposeful. Having different cultures helps with improving creativity, so we need to make services safe for different cultures. For Aboriginal and Torres Strait Islander communities promoting successful ageing is key to mentoring and ensuring there are positive role models for middle aged and young Aboriginal and Torres Strait Islander peoples. Older Aboriginal and Torres Strait Islander people hold knowledge and wisdom which is transferred through generations (Venessa Curnow, 2011).<sup>2</sup>*

### Elders

*... age does not necessarily designate a person as an Elder, however Elders may be recognised differently in each community. Different cultural protocols on the status of Elder apply to different local communities. An Elder is acknowledged by a community as having made a contribution to the community and as having cultural knowledge and status (NSW Aboriginal Community Care Gathering Committee, 2011, *Challenge, Change & Choice*, Policy Position, page 5).*

### Carers

While few Aboriginal people identify themselves as 'carers', many have significant caring responsibilities. Older Aboriginal people, in particular, frequently have multi-generational caring roles, including looking after grandchildren and great grandchildren (Marj Tripp, 2003).<sup>3</sup> Similarly, a number of people may share the role of carer of an older person. The concept of 'primary carer' may not therefore be relevant.

Community care providers can advocate on behalf of Aboriginal people to assist them to obtain appropriate support and entitlements as carers.

<sup>1</sup>This Briefing uses the term 'Aboriginal and Torres Strait Islander' in line with the practice of organisations such as the Secretariat of National Aboriginal and Islander Child Care Inc (SNAICC) unless directly quoting other sources, in which case the author's original language is preserved, or unless the research referred to was conducted only with Aboriginal people. The Australian Government's working definition of an Aboriginal Australian is someone who is a descendant of an Aboriginal Australian, who identifies as Aboriginal and who is recognised as Aboriginal by members of their community (National Aboriginal Community Controlled Health Organisation, 2012).

<sup>2</sup>Venessa Curnow is an Ait Koedal and Sumu woman, tracing her ancestry from Saibai Island in the Torres Strait and Keith in South Australia. She has been involved in the health and aged care industry for the past sixteen years and has held various positions as a registered nurse, clinical nurse and consultant in urban, rural and remote areas.

<sup>3</sup>Marj Tripp is a descendant of the Ramindjeri people of the Ngarrindjeri nation. Marj has worked in the area of Aboriginal Health and Community programs for over 40 years and has been instrumental in initiating many programs and institutions that benefit Aboriginal people.

## The health and wellbeing of older Aboriginal and Torres Strait Islander people

The concept and meaning of health to Aboriginal people is multi-dimensional, deeply embedded in culture and spirituality, and embraces all aspects of life and living.

*To us, health is about so much more than simply not being sick. It's about getting a balance between physical, mental, emotional, cultural and spiritual health. Health and healing are interwoven, which means that one can't be separated from the other (Dr Tamara Mackean, Australian Indigenous Doctors' Association, quoted in Koori Mail, 2008).*

It is important to understand that the colonisation of Australia has had devastating effects on Aboriginal and Torres Strait Islander people, the impact of which continues today. Aboriginal and Torres Strait Islander people have faced, and continue to face, many inequities which are clearly illustrated by the differences in health and life expectancy between Aboriginal and Torres Strait Islander people and non-Indigenous Australians.

### Demographics and life expectancy

According to census data, there were almost 550,000 Aboriginal and Torres Strait Islander people in Australia in 2011, comprising approximately 2.5% of the population. Of these, 2.25% were Aboriginal, 0.15% were Torres Strait Islanders and 0.1% were people who identified themselves as both Aboriginal and Torres Strait Islander (Australian Bureau of Statistics, 2011a). However, it is acknowledged that, for various reasons, a significant number of Aboriginal and Torres Strait Islander people - estimated at more than 110,000 - were not included in the census count (ABS, 2011b). Undercounting is problematic because census data is used by governments to assess the need for, and allocate resources to, relevant programs and services (Taylor & Biddle, 2008).

Aboriginal and Torres Strait Islander people have poorer health and higher rates of disability than non-Aboriginal people. In addition, there is a significant gap in life expectancy between Aboriginal and Torres Strait Islander Australians and non-Aboriginal Australians. This means that a lower percentage live to old age

than do non-Aboriginal people. In 2011 fewer than 4% of the Aboriginal and Torres Strait Islander population were aged 65 years and over, compared to 14% of the population as a whole (ABS, 2011a). The population of older Aboriginal and Torres Strait Islander people is, however, ageing rapidly and there are a growing number of 'survivors' over the age of 75.

### Intergenerational disadvantage and other factors contributing to the gap in life expectancy

Multiple interconnected historical, social, economic and political factors influence the ageing experience of Aboriginal and Torres Strait Islander people and contribute to poorer health and the gap in life expectancy.

*We need to find the causes of profound stress, across the life span that have led to a smoking rate which is four times that of non-Indigenous people; rather than take the simplistic view that smoking cessation will in itself "close the gap". We need to attack the socioeconomic causes of obesity, across the life span, rather than blame adult Aboriginal people for the high rates of mid-life diabetes. We need to recognise that a majority of Aboriginal people do not drink alcohol at all and that we therefore need to attack the underlying causes of alcohol and drug dependency; rather than focus only on the current "drinking problems" in some Aboriginal communities. In particular we need to embrace methods to provide a secure family environment, equal access to early childhood programs, better educational opportunities for Aboriginal children, and quality jobs for Aboriginal youth, as essential to closing the gap - in addition to the importance of health measures and better health care in mid-life and old age (Professor Tony Broe, 2008).*

Colonisation, combined with the discriminatory and racist policies of early Australian governments and the forced removal of Aboriginal and Torres Strait Islander children from their families, culture and country, has led to ongoing physical, spiritual and emotional harm and high levels of intergenerational disadvantage. Barriers to education, training, economic and social participation have led to high levels of poverty and poor living conditions, which in turn increases the risk of disability and early death from chronic disease (AIHW, 2011b).

Dispossession from land and country meant that Aboriginal and Torres Strait Islander peoples lost their access to food, water, traditional medicine and shelter, as well as the displacement of their spiritual connection to country. This has had lasting effects.

*Since white people first came to Australia in 1788, Indigenous people have experienced displacement, been the targets of genocidal policies and practices, had families destroyed through the forcible removal of children, and continue to face the stresses of living in a racist world that systematically devalues Indigenous culture and people. Such experiences have profound effects on health and social and emotional well being, for individual families and communities (Purdie et al., 2010:38).*

The forced removal of children – the Stolen Generations – was not a single event but occurred over decades (Haebich, 2000). It continues to have a significant impact on the social and emotional wellbeing of older Aboriginal and Torres Strait Islander people today, many of whom were themselves removed from their families and country (Purdie et al., 2010).

The impact of these losses may compound, or be compounded by, poor physical or psychological health that develops as part of the ageing process.

### **Resilience**

Resilience is characteristic of many older Aboriginal and Torres Strait Islander people. Despite often having lived a life littered with loss and grief and immense struggle they have continued to celebrate their culture and identity with courage.

*Today's Elders are the survivors of two centuries of cultural and racial domination. Through all the hardship, traditions of resilience and courage were established and, despite detention on missions, removal of children, banning of Aboriginal languages and spirituality, enforced Christianisation and European education ... Indigenous people still maintain their culture and identity (Aboriginal Community Elders Service and Harvey, 2003:7).*

### **Dementia and Alzheimer's Disease**

In recent years dementia has emerged as a significant health issue among Aboriginal and Torres Strait Islander people at comparatively young ages (under 75 years) (AIHW, 2011a). The incidence of dementia is expected to increase as life expectancy improves (Garvey et al., 2011).

The prevalence of dementia among Aboriginal Australians is difficult to quantify. Research conducted in the remote Kimberley in 2006 found the prevalence to be 12.4%. This is up to 5.2 times greater than in the overall Australian population (Alzheimer's Australia, 2007). The research further indicated that prevalence was higher among males (while in the general community the rate is higher among females). Importantly, it demonstrated that dementia of the Alzheimer's type was most common. Preliminary analyses of research undertaken by the Koori Growing Old Well Study (KGOWS) in urban and rural Aboriginal communities in NSW found similar prevalence rates.

As in the broader Australian population there are many misconceptions about dementia (Garvey et al., 2011). Dementia is perceived and experienced in many different ways but is often not recognised as a medical condition. Some have described dementia as a 'sick spirit' (Alzheimer's Australia, 2006:2).

A diagnosis of dementia can be particularly distressing for Aboriginal and Torres Strait Islander people because of the role of Elders in passing on cultural knowledge to younger generations orally, which requires a reliance on memory. As a result, it is not only individuals and families who are affected by dementia, but entire communities (Arkles et al., 2010). Communities may also become distressed when a person with dementia breaks cultural taboos and norms (Arkles et al., 2010). The accurate assessment of dementia among Aboriginal and Torres Strait Islander people is essential so that appropriate services can be provided.

The causes of Alzheimer's disease are unknown. However, risk factors include past head injuries, low levels of physical activity, high blood pressure, diabetes, high cholesterol and having a parent who had the disease (Neuroscience Research Australia, n.d.). The social and health profiles of Aboriginal and Torres Strait Islander people show many of the risk factors associated with developing dementia in later life.

## Community care services for older Aboriginal and Torres Strait Islander people

### Consultation

At an organisational level, building genuine relationships with Aboriginal and Torres Strait Islander communities through respectful consultation is the cornerstone of developing appropriate, targeted and responsive services.

*Respect means ensuring that Aboriginal and Torres Strait Islander people are involved in the planning and implementation process of policies, programs and services. Obtaining funding to establish services specifically for Aboriginal and Torres Strait Islander families before relationships are forged is seen as disrespectful by Aboriginal and Torres Strait Islander people (NSW Aboriginal Community Care Gathering Committee, 2011, Challenge, Change & Choice, Policy Position, Recommendation 11).*

Advice and direction should be sought from Elders and leaders of each community about the most appropriate way to access the community. For example, when the KGOWS team works with Aboriginal communities, their first step is to make contact with local Aboriginal people. At this first contact, the team can ask who within the community is the most appropriate contact, and what to do in order to be invited into the community and introduced to the appropriate groups, organisations or members of the community to ask for approval to proceed further with consultation. Genuine consultation with honesty and respect is highly valued but can take time, and this needs to be factored into planning. Sometimes Aboriginal people may have to prioritise the needs of, and obligations to, their own communities ahead of responsibilities to mainstream organisations. It is also important to keep in mind that Aboriginal people often feel over-researched and over-consulted (particularly when they see little change or few tangible outcomes).

### Access to community care services

In acknowledgment of their poorer health and lower life expectancy, Aboriginal and Torres Strait Islander people are included in national aged care planning and are eligible to receive community/home care packages from 50 years and over as distinct from age 65 years and over for non-Aboriginal people (Australian

Government Department of Health and Ageing, 2012:77). More recently it has been suggested that, while well intentioned, this policy may contribute to the stereotyping of Aboriginal and Torres Strait Islander people over the age of 50 as dependent and in need of care (Cotter et al., 2012).

Many older Aboriginal and Torres Strait Islander people experience problems accessing services. This may be because of social isolation, personal and health problems, or because available services are not perceived as culture-friendly. Some older Aboriginal people are fearful of, or are reluctant to engage with, medical and welfare systems. Many wish to be cared for in their own communities where they are close to family and kin, and to be able to die on their land (Arkles, et al., 2010).

However, it is important not to make assumptions about the types of services preferred. Some people want their health and/or care needs met by Aboriginal controlled community services such as Aboriginal Medical Services or Aboriginal aged care organisations. Others may choose to use mainstream services, or mainstream services that employ Aboriginal and Torres Strait Islander staff.

These preferences may be influenced by family, cultural and historical experiences, the complexity of individual health needs, language issues, cost and service availability. In some areas, especially remote areas, Aboriginal people have no choice about what type of service to access as there may only be one local provider.

### Time

Providing community care services to Aboriginal and Torres Strait Islander people may be more time consuming, intensive and complex than providing services to non-Aboriginal people. Additional time will often be required to build genuine trusting relationships.

*Leading practice in community care to Aboriginal and Torres Strait Islander older people ensures that visits include time to build trust, a cup of tea, a chat. Often Aboriginal and Torres Strait Islander people are storytellers; and the details needed for assessments etc are often in the story (NSW Aboriginal Community Care Gathering Committee, 2011, Challenge, Change & Choice, Policy Position, Guiding Principle 13).*

This may mean avoiding asking lots of questions, and allowing periods of silence while the person considers what has been said, giving plenty of time for them to tell their story (Mental Health First Aid, 2008).

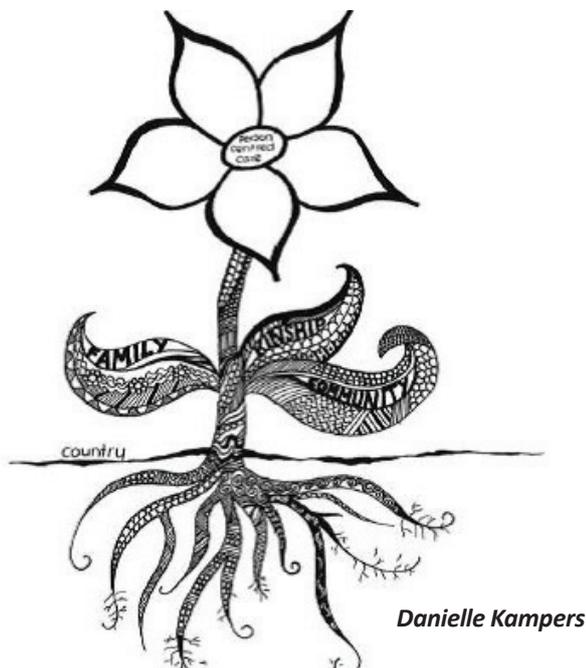
**Communication**

Respectful ways of communicating (including body language, seating position and use of certain words) may differ from community to community and region to region, especially between rural and remote areas. In some communities, for example, eye contact is considered as staring, and may make the person feel as though they are being judged (AMHFA, 2008).

**Person-centred care**

Western approaches to person-centred care tend to focus on the individuality of the particular person receiving care, and of their immediate family members. A person-centred approach to community care practice with Aboriginal and Torres Strait Islander people would take into account the central importance of connection to family, kinship networks, communities and country (McMillan et al., 2010).

Drawing on the work of Professor Tom Kitwood (1937-1998), McMillan et al. (2010:165) have provided the illustration by Danielle Kaspers as an example of a model which may represent more accurately and sensitively person-centeredness for Aboriginal and Torres Strait Islander people (reproduced with the permission of the authors).



**End of life**

Many older Aboriginal and Torres Strait Islander people live away from their original lands or country. This is often felt as a greater loss at times of stress, including towards the end of life. Many older people have a strong desire to go back to their country at these times, and doing so can be more important to them than receiving health treatment (Indigenous Palliative Care Project, 2009).

Community care providers can play a role in facilitating this, in partnership with palliative care and other community health services, families and communities.

**Practice Implications**

**The key foundation to building a relationship is respect and this is achieved through understanding ... when non-Indigenous people develop and demonstrate respect for Aboriginal and Torres Strait Islander people, their culture and spirituality, and the strength and resilience with which Aboriginal and Torres Strait Islander people have preserved their family connections, communities and culture, they are likely to establish respectful interpersonal relationships with Aboriginal and Torres Strait Islander individuals and families (SNAICC, 2010: 1, 55).**

**Respecting diversity:** The great diversity of Aboriginal and Torres Strait Islander cultures, peoples and communities means that appropriate and acceptable ways of interacting and communicating with Aboriginal and Torres Strait Islander people will vary from community to community. Respect should be paramount in all interactions.

**Understanding:** Engaging with and developing partnerships with local Aboriginal and Torres Strait Islander communities and organisations can be a key strategy for improving older Aboriginal and Torres Strait Islander people’s access to community care. Partnerships may involve brokerage arrangements and/or helping to build the capacity of Aboriginal community care organisations. They may enable mainstream community care organisations to understand how they are currently perceived and what they may need to change to make their services more appropriate, flexible and responsive to cultural needs.

*Practice Implications continued...*

**Cultural competence:** Cultural competence needs to be reflected in leadership and in the knowledge, values, skills and attributes of all staff within an organisation. Cultural competence training for staff of mainstream services will increase the likelihood that their services are sensitive to the needs of Aboriginal and Torres Strait Islander people. It enables individual workers to gain skills and knowledge, an understanding of their own culture and how this affects their practice, and an understanding of how to engage with people from Aboriginal and Torres Strait Islander backgrounds.

**Employment practices:** Service provider organisations should make a commitment to employ Aboriginal and Torres Strait Islander staff, so that clients can be looked after by Aboriginal and Torres Strait Islander careworkers when preferred.

**Service provider audit:** Consider undertaking an organisational audit of some of these issues to determine your service's strengths and weaknesses and where changes need to be made. For example, *Working with Aboriginal people and communities* - Health and Community Services Audit at [www.whealth.com.au/mtww/documents/MTWW\\_Audit\\_Tool.pdf](http://www.whealth.com.au/mtww/documents/MTWW_Audit_Tool.pdf)

### Our commitment to reconciliation

The Benevolent Society is committed to promoting the economic, political, and social inclusion of Aboriginal and Torres Strait Islander people and to upholding their rights, needs and aspirations. We recognise the ongoing impact of the harsh injustices and exclusion inflicted on Aboriginal and Torres Strait Islander people since colonisation. First Australians continue to face ongoing disadvantage and exclusion and we have a shared responsibility as a nation to accept the challenge of reconciliation.

The Benevolent Society's Reconciliation Action Plan (RAP) 2012-2015, *Walking Together*, reinforces our commitment to Australia's reconciliation process and maps out our own path to reconciliation through respect, the creation of relationships, and opportunities with Aboriginal and Torres Strait Islander people.

### Discussion Guide

1. Does your organisation have protocols for engaging with local Aboriginal and Torres Strait Islander communities?
2. Do you have relationships with your local Aboriginal and/or Torres Strait Islander communities or know who they are?
3. Can you identify some local cultural guides who can assist your organisation to be more responsive to the needs of older Aboriginal and Torres Strait Islander people in your area?
4. Do you ask local Traditional Owners to perform Welcome to Country ceremonies, and how do you recognise this practice (financial and/or otherwise)?
5. Do you know how accessible your services are perceived to be, by older Aboriginal and Torres Strait Islander people in your area? How might you go about finding out?
6. Does your service adopt each client's own definition of 'family' which may include, but not be limited to, an extended kinship network? How might you go about learning about these networks and connections of an older client?
7. A person can't always be identified as an Aboriginal or Torres Strait Islander person by looks. Do you always ask clients 'are you of Aboriginal and/or Torres Strait Islander descent?' and how they would like to be addressed?
8. Does your organisation provide cultural or ceremonial leave for Aboriginal and Torres Strait Islander staff to participate in important events in their community?
9. Are staff encouraged to attend important Aboriginal and Torres Strait Islander community events such as NAIDOC week?
10. Are staff supported to understand how the accumulated impact of colonisation, dispossession, racism and disempowerment affects the current health status of older Aboriginal and Torres Strait Islander people and their use of health and community services?
11. Does your service have a Reconciliation Action Plan?

## Helpful resources

### NATIONAL

Australian Indigenous HealthInfoNet  
[www.healthinfonet.ecu.edu.au](http://www.healthinfonet.ecu.edu.au)

Reconciliation Australia [www.reconciliation.org.au](http://www.reconciliation.org.au)

Centre for Cultural Competence Australia  
[www.ccca.com.au/](http://www.ccca.com.au/)

Australian Institute of Aboriginal and Torres Strait  
Islander Studies and Map of Aboriginal Australia  
[www.aiatsis.gov.au](http://www.aiatsis.gov.au)

Alzheimer's Australia [www.fightdementia.org.au/  
understanding-dementia/aboriginal--torres-strait-  
islander-groups.aspx](http://www.fightdementia.org.au/understanding-dementia/aboriginal--torres-strait-islander-groups.aspx)

### QLD

Queensland Aboriginal and Islander Health Council  
[www.qaihc.com.au](http://www.qaihc.com.au)

### SA

Council of Aboriginal Elders of SA [www.caesa.org](http://www.caesa.org)

### VIC

Centre for Cultural Diversity in Ageing  
[www.culturaldiversity.com.au](http://www.culturaldiversity.com.au)

Victorian Government Strengthening Home and  
Community Care (HACC) in Aboriginal Communities  
strategy [www.health.vic.gov.au/hacc/downloads/pdf/  
shac\\_strategy\\_jan08.pdf](http://www.health.vic.gov.au/hacc/downloads/pdf/shac_strategy_jan08.pdf)

### NSW/ACT

Working with Aboriginal people and communities-  
Health and Community Services Audit [www.whealth.  
com.au/mtww/documents/MTWW\\_Audit\\_Tool.pdf](http://www.whealth.com.au/mtww/documents/MTWW_Audit_Tool.pdf)

Aboriginal Health & Medical Research Council of New  
South Wales (AH&MRC) [www.ahmrc.org.au](http://www.ahmrc.org.au)

Aboriginal dementia learning resources, including  
assessment guide and A guide to dementia for  
Aboriginal people [www.adhc.nsw.gov.au/publications/  
aboriginal](http://www.adhc.nsw.gov.au/publications/aboriginal)

Sydney Indigenous Aged Care Scoping Study  
[www.agedservices.asn.au/docs/community-care-  
documents/click-here-.pdf?sfvrsn=0](http://www.agedservices.asn.au/docs/community-care-documents/click-here-.pdf?sfvrsn=0)

NSW Aboriginal Community Care Gathering Committee  
c/- [www.ncoss.org.au/content/view/12/26/](http://www.ncoss.org.au/content/view/12/26/)

Koori Growing Old Well Study, Neuroscience Research  
Australia [www.neura.edu.au/aboriginal-ageing](http://www.neura.edu.au/aboriginal-ageing)

### NT

Menzies School of Health Research Cultural Protocols  
for working in Indigenous communities  
[http://remotehealthatlas.nt.gov.au/cultural\\_protocols  
for\\_working\\_in\\_indigenous\\_communities.pdf](http://remotehealthatlas.nt.gov.au/cultural_protocols_for_working_in_indigenous_communities.pdf)

### WA

Western Australian Indigenous Health Promotion  
Network [www.healthinfonet.ecu.edu.au/states-  
territories-home/wa/WAIHPN](http://www.healthinfonet.ecu.edu.au/states-territories-home/wa/WAIHPN)

**We welcome feedback on this Briefing.**

**A full list of references can be accessed on The Benevolent Society's website.**



**Neuroscience  
Research Australia**  
*Discover. Conquer. Cure.*

Neuroscience Research Australia (NeuRA) is an independent not-for-profit research institute. The Koori Growing Old Well Study is part of the Aboriginal Health and Ageing Research Program based at NeuRA. It aims to increase knowledge about healthy ageing and dementia in Aboriginal people in urban and regional areas in New South Wales.

## We are The Benevolent Society

We help people change their lives through support and education, and we speak out for a just society where everyone thrives.

We're Australia's first charity. We're a not-for-profit and non-religious organisation and we've helped people, families and communities achieve positive change for 200 years.

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## Consultation undertaken by the Koori Growing Old Well Study Project Team that informed The Benevolent Society's Research to Practice Briefing 8: *Working with older Aboriginal and Torres Strait Islander people*

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The Benevolent Society's *Research to Practice Briefing 8: Working with older Aboriginal and Torres Strait Islander people*, was informed by prior research by, and knowledge of, the members of the Koori Growing Old Well Study Project Team.

The "Koori Growing Old Well Study" (KGOWS) was funded by the National Health and Medical Research Council (NHMRC) and approved by the Aboriginal Health & Medical Research Council (AH&MRC). KGOWS involves Aboriginal Investigators, employs Aboriginal researchers, and has been working in partnership with Aboriginal Community Controlled Organisations since 2008.

KGOWS team members' history of consultation with Aboriginal communities and community participation includes:

- Aboriginal community consultations and community service development with the La Perouse community from 2000 to 2006 by KGOWS team members Gail Daylight, Professor GA (Tony) Broe and Aboriginal Health Workers. This consultation led to establishment of:
    - the La Perouse Aboriginal Chronic Care Working Group (2000 to 2005), which became the La Perouse Aboriginal Community Health Centre Advisory Group in 2006 and is still operational;
    - the La Perouse Aboriginal Community Health Centre (2005); and
    - the Aboriginal Population Health and Ageing Research Group, Neuroscience Research Australia (2007).
  - Partnerships with La Perouse Local Aboriginal Land Council; Tharawal Aboriginal Corporation (AMS) Campbelltown; Durri ACMS Kempsey; Darrimba Maarra Aboriginal Health Clinic Nambucca; and Galambila Aboriginal Health Service (AHS) Coffs Harbour.
  - Aboriginal community consultations, commencing in 2007, across NSW communities at La Perouse, Campbelltown, Western Sydney (Mt. Druitt), Kempsey, Nambucca and Coffs Harbour from 2007.
  - Establishment of Aboriginal Guidance Groups, comprised of community members to advise on cultural appropriateness, local recruitment and issues arising from research.
  - Establishment of an Aboriginal Reference Group with one Aboriginal Guidance Group Member from each community and three independent Aboriginal researchers (Mr. Terry Mason, University of Western Sydney; Professor Kerry Arabena, Monash University; and Dr Kelvin Kong, University of Newcastle).
  - Pilot studies of interviews with 30 Aboriginal volunteers, from metropolitan and rural/urban sites, to examine content of the study, to test the acceptability and appropriateness of interviews used, and the length of interviews.
  - Development of a comprehensive manual to guide researchers in their fieldwork, and a mandatory two day training workshop for all study personnel in both cultural issues and cognitive screening.
  - An extension of initial NHMRC funding for four Aboriginal research staff for one year to funding for ten Aboriginal Researchers over five years, as well as further funding from the Australian Government Department of Health and Ageing (DoHA) and NSW Government Ageing, Disability and Home Care (ADHC) and other sources to carry out the specific aims of KGOWS: to build community capacity in aged care; increase dementia knowledge; and inform communities about dementia care.
  - KGOWS has a policy of no research without Aboriginal partnerships, community capacity building, Aboriginal research staff, service development and the support of local communities. Aboriginal Researchers are Investigators on all studies.
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# Working with older Aboriginal and Torres Strait Islander people

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