

SHARING THE WISDOM OF OUR ELDERS



FINAL REPORT 2019



Aboriginal
Health & Ageing Program



NeuRA

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ACKNOWLEDGEMENT OF COUNTRY

We acknowledge and pay respects to the Traditional Custodians of Gumbaynggirr, Dunghutti and Bidjigal Country, and the lands of the Dharug, Eora and Dharawal nations where this work was carried out. We sincerely thank the Elders who guided the work and provided feedback as the work progressed and to those who reviewed and commented on the final report.



**Sincere thanks are extended to the Elders
who entrusted us with their stories.**

Cover artwork: *As Far as the Eye Can See* by Alison Williams, Gumbaynggirr woman and Gallery Director Wadjar Gallery Yarrawarra Aboriginal Cultural Centre, Corindi Beach NSW.

This artwork symbolises the electrical connections of brain matter in the format of an eye. It speaks to stimulation and identifying through vision and connection to Country. A full description is located on page 25.

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SHARING THE WISDOM OF OUR ELDERS

FINAL REPORT 2019

Understanding and Promoting
Healthy Ageing with Older Aboriginal
and Torres Strait Islander Australians



Aboriginal
Health & Ageing Program

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Who We Are

Neuroscience Research Australia (NeuRA) is an independent, not-for-profit research institute based in Sydney, Australia. NeuRA is affiliated with the University of New South Wales (UNSW) and is recognised as a world leader in brain and nervous system research, with an objective to prevent, treat and cure brain and nervous system diseases through research. The Aboriginal Health and Ageing Program, established in 2008, works in partnership with Aboriginal communities throughout NSW to better understand, prevent and reduce the burden of dementia, which we now know is three times more common for older Aboriginal and Torres Strait Islander people.

Investigators

- **Dr Kylie Radford**, Research Fellow, Aboriginal Health and Ageing Program NeuRA and Conjoint Senior Lecturer, School of Medical Sciences, UNSW
- **Associate Professor Kim Delbaere**, Principal Research Scientist, NeuRA and School of Public Health and Community Medicine, UNSW
- **Professor Gail Garvey**, Senior Principal Research Fellow and Deputy Division Leader, Wellbeing and Preventable Chronic Diseases Division, Menzies School of Health Research
- **Professor Tony Broe**, Senior Principal Research Scientist, NeuRA and Conjoint Professor of Geriatric Medicine, School of Public Health and Community Medicine, UNSW
- **Dr Wendy Allan**, Research Manager, Aboriginal Health and Ageing Program, NeuRA
- **Ms Gail Daylight**, Honorary Research Associate, Aboriginal Health and Ageing Program, NeuRA
- **Mr Terrence Donovan**, Research Translation Coordinator, Aboriginal Health and Ageing Program, NeuRA
- **Auntie Margaret Anderson**, Research Assistant, Aboriginal Health and Ageing Program, NeuRA
- **Ms Alison Timbery**, Research Translation Coordinator, Aboriginal Health and Ageing Program, NeuRA
- **Ms Kylie Sullivan**, Research Assistant, Aboriginal Health and Ageing Program, NeuRA
- **Ms Madeleine Nichols**, Research Assistant, Aboriginal Health and Ageing Program, NeuRA
- **Dr Louise Lavrencic**, Post-doctoral Fellow, Aboriginal Health and Ageing Program, NeuRA and Conjoint Associate Lecturer, School of Public Health and Community Medicine, UNSW

Abbreviations used in this report

- **KGOWS**: Koori Growing Old Well Study
- **NDIS**: National Disability Insurance Scheme
- **NeuRA**: Neuroscience Research Australia
- **UNSW**: University of New South Wales



Key Messages

- Aboriginal and Torres Strait Islander Australians are living longer but with population ageing, dementia is an emerging health issue
- A significant proportion of dementia is linked to modifiable risk factors and we can learn about prevention from older Aboriginal and Torres Strait Islander people who are ageing well
- Reducing dementia risk is a life course process; there are a number of ways in early, mid and late life to develop and maintain brain health, in order to grow old well
- The *Sharing the Wisdom of Our Elders* project highlights five overarching and intersecting themes of primary importance to Elders for growing old well: Culture, Sacred Grounds, Spirituality, Dreamtime, and Sharing the Wisdom of Our Elders. Underlying 'growing old well' themes were also identified and included widely recognised as well as more culturally specific ways to reduce dementia risk and age well:
 - Connections to Country and culture
 - Respect yourself, the Elders and all the mob
 - Resilience
 - Getting together, yarning, passing on knowledge
 - Keeping healthy to live a long life
 - Saying no to smoking, alcohol and drugs
 - Education
- Healthy ageing programs and aged care services available to Elders are often Aboriginal-specific, in line with community preferences, and these service providers are generally working hard to meet the cultural, health and wellbeing needs of Elders through a holistic and flexible approach to service delivery
- The main gaps and challenges identified by service providers include need for greater:
 - Investment in the Aboriginal and Torres Strait Islander aged care workforce to meet current and future demands
 - Education for families regarding ageing and dementia
 - Education and support to access the aged care system
 - Trauma-informed and healing-centred approaches to aged care services
 - Transport and respite for clients and their families

Background

Sharing the Wisdom of Our Elders is an outcome of the Koori Growing Old Well Study (KGOWS)[1], a longitudinal cohort study which aims to identify risk and protective factors for dementia and other age-related chronic conditions, as well as promote ageing well with Aboriginal and Torres Strait Islander Australians (respectfully referred to hereafter as Aboriginal) from urban and regional communities.

As a population, Aboriginal Australians are ageing rapidly, with an increasing number and proportion of older people in all communities. Unacceptable disparities ('gaps') in mortality remain, but average life expectancy is increasing, and is currently 72-76 years for Aboriginal Australians. At older ages, life expectancy for Aboriginal people is closer to that of non-Indigenous Australians (ABS, 2019). Older people have a vital role in Aboriginal communities, in terms of leadership, caregiving and continuity of culture. As such, the health and wellbeing, and aged care needs, of older Aboriginal people are emerging priorities.

In 2010-2012, 336 Aboriginal people aged 60+ across five NSW urban and regional communities including La Perouse, Campbelltown, Kempsey, Nambucca Heads and Coffs Harbour took part in the KGOWS baseline study (KGOWS-I). The study documented older people's health across their entire lifespan and considered the impact of social, cultural and biomedical factors on the way people age.

Early life factors that affect physical health and brain function throughout the lifespan start with health during pregnancy and birth as well as early life health and environment, adverse childhood events, formal and informal educational experiences, social and cultural enrichment, and parenting.

Midlife factors examined included physical health and chronic diseases (high blood pressure, diabetes, cholesterol, obesity, heart and lung disease, alcohol and drug use), as well as continuing education through jobs and training.

Late life factors focused on cognitive, social and emotional wellbeing, understanding the experience of ageing and dementia in Aboriginal communities, the frequency of cognitive changes (e.g., memory loss) and different dementia types, how to appropriately assess dementia in urban and regional Aboriginal communities, and access to aged care services for older Aboriginal Australians and their carers.

We conducted a follow-up study six years later (KGOWS-II; 2016-2018), to learn more about the changes associated with growing older and the factors contributing to ageing well for Aboriginal people. One hundred and sixty-five KGOWS participants took part in the follow-up study. KGOWS-II included questions about people's experiences of growing older, changes in health and wellbeing, and about needs for, and use of, general health, aged care and dementia services in NSW.

What We Found in KGOWS

Higher rates of dementia at younger ages [2]: Dementia is about three times more common in older Aboriginal people (Fig. 1).

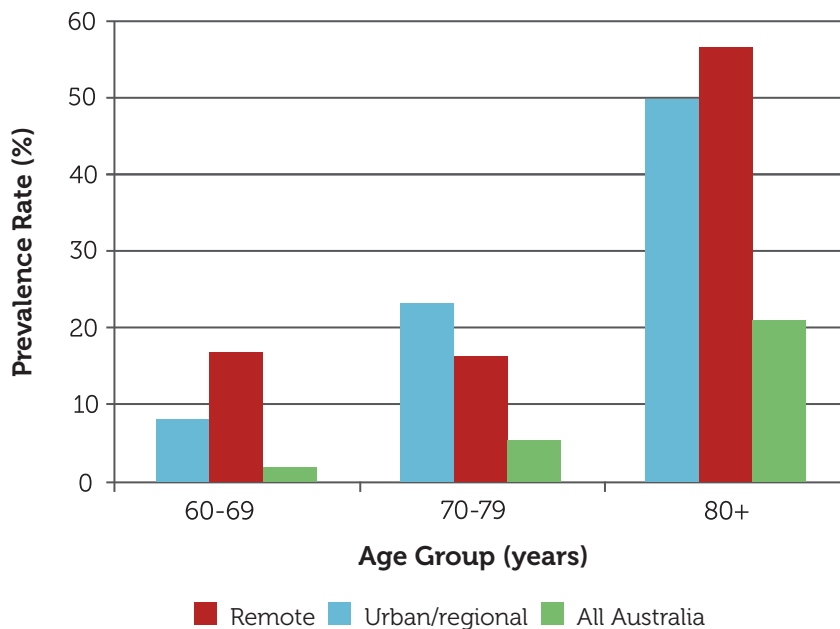


FIGURE 1: Dementia prevalence for Aboriginal Australians shown in blue (urban/regional NSW) and red (remote WA), compared to rates across all Australians.


What seems to be increasing the risk of dementia?

KGOWS-I (snapshot in time) [3] showed:

- Living longer lives
- Childhood stress and trauma
- Limited work opportunities (linked to education)
- Brain injury (stroke, head trauma/concussion, epilepsy)

KGOWS-II (over 6-years follow-up) [4] showed:

- Living longer lives
- Limited work opportunities and low education
- Significant hearing and vision loss in mid-late life
- Low physical activity in late life
- Polypharmacy (>4 medications)
- Men at higher risk
- APOE-ε4 (genetic risk factor for Alzheimer's disease)



By identifying modifiable risk factors for dementia in Aboriginal Australians, we can aid the development and implementation of targeted prevention or 'risk reduction' strategies across the lifespan, to promote healthy ageing and reduce the burden of dementia.

Although the high rates of cognitive decline and dementia are concerning and need to be addressed, it is also important to recognise that most older Aboriginal people do not have dementia and many are ageing well. So, what can we learn from these older people?

Likely Protective Factors

- Connection to land and culture
- Physical activity and maintaining healthy bodies
- Social engagement
- Resilience
- Good education and jobs
- Strong families and social support

In order to translate the research findings from KGOWS and highlight the healthy ageing stories of our participants, the *Sharing the Wisdom of Our Elders* project was developed.

For more information about KGOWS and dementia in urban and regional Aboriginal communities, see the following key references:

- Radford K, Mack HA, Robertson H, Draper B, Chalkley S, Daylight G, Cumming R, Bennett H, Jackson Pulver L, Broe GA. (2014). The Koori Growing Old Well Study: Investigating aging and dementia in urban Aboriginal Australians. *International Psychogeriatrics* 26(6): 1033-1043.
- Radford K, Mack HA, Draper B, Chalkley S, Daylight G, Cumming R, Bennett H, Delbaere K and Broe GA. (2015). Prevalence of dementia in urban and regional Aboriginal Australians. *Alzheimer's & Dementia* 11: 271-279.
- Radford K, Lavrencic LM, Delbaere K, Draper B, Cumming R, Daylight G, Mack HA, Chalkley S, Bennett H, Garvey G, Hill T, Lasschuit D, Broe GA. (2019). Factors associated with the high prevalence of dementia in older Aboriginal Australians. *Journal of Alzheimer's Disease*, doi: 10.3233/JAD-180573.



About this Project

This project, *Sharing the Wisdom of Our Elders*, is in response to research highlighting limited awareness of ageing and dementia across Aboriginal community members [5]. Additionally, there were requests from KGOWS partner communities for culturally meaningful, strength-focused and evidence-based education resources to increase knowledge of healthy brain ageing and dementia prevention with service providers and Aboriginal community members of all ages. Dementia, mostly Alzheimer's disease, is three times more common in older Aboriginal people and likely linked to preventable risk factors from early life onward [3]. This project will contribute to better services and outcomes through raising community awareness of healthy ageing across the life course.

In order to achieve this, the project involved three main components:

- 1. Report on health, resilience, social connectedness, and engagement with community and culture with a diverse group of older Aboriginal people who are “growing old well”**

This step draws upon quantitative findings from the KGOWS cohort, a representative sample of older Aboriginal people in urban and regional NSW, and the factors we have found that contribute to living longer, stronger lives. These findings are integrated throughout this report.

- 2. Share Elders' insights into the meaning of healthy ageing and stories of “growing old well” through development of engaging educational resources**

The importance of culture and Elders' stories that explore the meaning of good and healthy ageing from Aboriginal perspectives have been documented in KGOWS. Participants' responses to the open-ended question: “Over your lifetime, what have you learned is important for growing old well?” were analysed to determine the main factors people felt had contributed to their longevity and wellbeing in later life. This portion of the project represents the insights of Elders in both artwork and stories.

- 3. Identify current services and organisations and whether these align with the needs and expectations of the ageing Aboriginal population**

Semi-structured interviews were conducted with organisations and programs that provided services to Aboriginal Elders across urban and regional NSW partner communities. These interviews were analysed in order to identify service strengths and any gaps in meeting the identified needs of older Aboriginal people.

Our Partnering Communities

The partner communities involved in KGOWS were within the Local Government Areas of Coffs Harbour, Nambucca, Kempsey, Campbelltown and Randwick/ Botany Bay (La Perouse). These encompass the traditional Aboriginal Nations of the Gumbaynggirr, Dunghutti, Dharawal and Bidjigal peoples. Whilst our participants lived in these communities, it is important to note that many identified with mobs from all over Australia (Fig. 2). These included the lands of the Anaiwan, Arrernte, Awabagal, Bardi, Bawgutti, Bidjigal, Biripi, Bundjalung, Darug, Eora, Gamilaraay/Kamilaroi, Goreng Goreng, Gundungurra, Gunybaray, Guringai, Kalkadun, Kurnai, Nganyaywana, Ngunawal, Nyungan, Thaua, Wadi Wadi, Walbanga, Wiradjuri, Wonnarua, Worimi, Yaegl, Yorta Yorta, Yuggera, Yuin and Yuwalarai peoples.



FIGURE 2: KGOWS participants reported diverse cultural identities (depicted on the AIATSIS Map of Indigenous Australia); each red dot indicates an approximate locality of the traditional Nations identified by participants.

NeuRA Aboriginal Health and Ageing Program Team

Front Row (L-Rt): Kylie Radford, Terrence Donovan, Margaret Anderson, Tony Broe.

Top Row (L-R): Stacey Donovan, Wendy Allan, Rebecca Mann, Madeleine Nichols, Lauren Poulos, Ellen Finlay, Alison Timbery, Kylie Sullivan.

(Not pictured: Kim Delbaere, Belinda Ducker, Louise Lavrencic, Lena Slater and Sharon Wall.)



Project Timeline

●... March 2010 – September 2012

KGOWS-I participant interviews; quantitative data collection

●... July 2016 – April 2018

KGOWS-II participant interviews; qualitative data collection for current study

●... May 2018

Workshop: Qualitative data analysis; collaborative coding of KGOWS-II data

●... July 2018

Call for artworks; design of semi-structured interview for service providers

●... August – November 2018

Service provider study; environmental scan and interviews

●... October 2018

Selection of artworks

●... December 2018

Workshop: Collaborative coding of service provider interview data

●... March 2019

Workshop: Review/confirm outcomes with community partners

●... June 2019

Preliminary launch of project resources and outcomes: The Lowitja International Indigenous Health & Wellbeing Conference, Darwin; and Australian Dementia Forum, Hobart

●... September 2019


Final report reviewed by the NeuRA Aboriginal Health & Ageing Program Steering Committee (including community partners and Aboriginal & Torres Strait Islander reference group) prior to launch

Sharing the Wisdom of Our Elders

The Sharing the Wisdom of Our Elders project team respectfully acknowledges the dispossession of land, culture, language and family connections, and associated traumas for Aboriginal and Torres Strait Islander peoples. However, in response to our partner communities and The Lowitja Institute research priorities, this project focuses on the concept of Strong Elders, and addresses the question: “What is good and healthy ageing for Aboriginal and Torres Strait Islander people?”

As part of the KGOWS follow-up study, detailed responses from 118 participants to the question “Over your lifetime, what have you learned is important for growing old well?” were examined by our team of researchers for similarities, differences and interrelating issues, using qualitative data analysis techniques. This process led to the classification by consensus of five overarching themes deemed of primary importance to Elders. These were Culture, Sacred Grounds, Spirituality, Dreamtime, and Sharing the Wisdom of Our Elders, and are illustrated below.





Throughout this report, we refer to the stories, perspectives and wisdom presented as coming from Elders. We acknowledge the deep cultural significance of the term and position of being an 'Elder', further recognising that not all older people in Aboriginal and Torres Strait Islander communities are considered to be Elders. We respectfully use the term Elder in this report when we privilege the qualitative data and insights shared with us by older Aboriginal people in response to the open ended question. In contrast, we use the term 'KGOWS participants' when referring to quantitative data from the population-based cohort. Our aim is to represent clearly the differences in data sources and the ways of sharing information that we draw on in these overall findings.

Elders spoke of how Sacred Grounds – Connection to Country, Spirituality, and Dreamtime are all interconnected; and how maintaining these connections is critical for older Aboriginal people to living a good life and ageing well. As one Elder described:

"There's men's and women's places... and sacred sites, spiritual things. It's our belief, it's our religion."

(ID 401019:4-5)

This is in step with the holistic view of health and wellbeing, defined as 'not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total well-being of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life.' [6]

From these interconnected and overarching themes, seven underlying 'growing old well' (ageing well) themes were derived, which will be explored in detail throughout the following sections.

Summary of underlying 'Growing Old Well' themes

1. Connections to Country and culture
2. Respect yourself, the Elders and all the mob
3. Resilience
4. Getting together, yarning, passing on knowledge
5. Keeping healthy to live a long life
6. Saying no to smoking, alcohol and drugs
7. Education

Artworks are incorporated into this report to further emphasise and represent these themes, and in recognition of the significance of art and painting traditions, alongside storytelling. These were submitted in response to a call for artworks from Aboriginal artists as part of the second component of the *Sharing the Wisdom* project (see also, **Appendix A**). A total of seven artworks were selected for inclusion in this project, based on review of all submitted artworks and their descriptions (with the review panel being blind to the identity of submitting artists). The selection panel included Elders, Aboriginal community members and researchers, and non-Indigenous researchers, spanning the KGOWS partner communities.

“It makes me proud that we are able to keep our culture alive through our paintings and our stories, and it also helps me to be strong and confident in all aspects of my life.”

Glenny Naden, artist contributing to this project, December 2018

Sharing cultural knowledge and passing on sacred stories as one grows old was of utmost importance to Elders. This is further explained by one of the artists:

“In our Aboriginal culture, Elders are an important, invaluable and intrinsic link spanning across time, where they are connected to the past, they exist in the present and they administer wisdom for the future. Our Elders deserve our respect and admiration for their resilience, shared knowledge and experience, and their invaluable contribution to our communities and country.”

Glenny Naden, 2018

The *Sharing the Wisdom of Our Elders* project name was translated into Gumbaynggirr language by language teacher and Gumbaynggirr man, Mr Clark Webb (Executive Officer, Bularri Muurlay Nyanggan Aboriginal Corporation). In future, we hope to work with our existing partner communities to incorporate more traditional languages into our knowledge translation projects.

BALGARRAMBA NGIYAMBANDI JALUMGAL

GIRRWAA-GUNDI MIINDALAY

(English translation: sharing our old mob's cleverness)

Glenny Naden's painting *Sharing the Wisdom of Our Elders*, illustrates the major overarching themes of Culture, Dreamtime, Spirituality, Sacred Grounds, and Sharing the Wisdom of Our Elders, with reference to the impact of dementia on Aboriginal communities. Glenny Naden identifies as a Kabi Kabi, Wakka Wakka, Koa and Wiradjuri woman. See painting overleaf.




Sharing the Wisdom of Our Elders

Glennie Naden, a Kabi Kabi, Wakka Wakka,
Koa and Wiradjuri woman

"This painting represents the themes of Culture and Dreamtime, Spirituality, Sacred Grounds, Sharing the Wisdom of our Elders, and the effects of dementia on our ageing Indigenous population."

See opposite page for the full description.





“The **red section** at the top of the painting represents our Culture and Dreamtime, depicting the lands and rivers of our Aboriginal nations, as well as the importance of our people being skilled in reading the seasons by the sun, moon and stars. The Dreaming paths of our people encompasses the dreams of our people and the way that land and water was essential to their way of life and survival. The central meeting place represents our people for all time, past, present and future.

The red background represents the earth and the excitement, passion and pride we feel for our Land. It encompasses strength, power, and determination. These characteristics are symbolic of our People's fortitude and confirms the incredible resilience and cultural pride that we have inherited from our Elders, and indeed our Ancestors.

The **green section** of the painting represents the Spirituality of our people. This is defined as being at the core of our being, our Identity. The symbolic Tree of Life with its root systems portrays the aspects of a solid foundation, leading to spiritual sustenance in our relationships with one another and the surrounding environment. The green background characterises the colour of life, renewal, growth, and environmental harmony. This serves to remind us of the different stages in our lives and the nurturing and growth needed to survive and pass on our cultural knowledge.

In the **yellow section** of the painting, we acknowledge our Sacred Grounds. These are special places of significance for conducting our traditions and ceremonies.

The yellow background conveys enlightenment, remembrance, intellect and honour and are characteristics that are evocative of the activities associated with our traditional and sacred grounds, and the significant roles of Elders in these practices.

The **purple section** of the painting represents the Sharing of Wisdom by our Elders. The colour purple is a rare occurring colour in nature and is sometimes seen as having sacred meaning. The central symbol is a meeting place where knowledge is given, which then extends out to other members of the community.

The purple background is associated with royalty, wisdom, wealth, dignity, devotion, peace, mystery and pride. These traits are the very things that endear our Elders to us and helps us to give them the esteemed acknowledgement, respect and admiration that is deserving of them.

The **blue section** of the Painting represents how dementia has affected our Elders and thus our communities. The central symbol depicts the person with dementia, surrounded by another person who is administering love, comfort and support in this vulnerable period of life. The other symbols, depicted by a question mark and jigsaw puzzle, indicates the state of mind that is so prevalent in people with dementia.

The blue background symbolises trust, wisdom, confidence, intelligence and is beneficial to the mind and metabolism and causes a calming effect. It is anticipated that through further professional research and practice, a better quality of life and eventual cure for dementia will be found.

At the centre of the whole of the painting is the brain, whose primary function includes relaying information between itself and the body. It is central to who we are, where our place is, and where our destiny lies.”


Connections to Country and Culture

Connection to Country has been shown to have a key influence on the wellbeing of Aboriginal people among the Yorta Yorta nation, Boonwurrung and Bangerang tribes [7]. This previous study found that recognition of an individual's traditional custodian roles strengthened cultural identity and that caring for Country increased people's self-esteem and spiritual connection to the land. In line with this finding, over three quarters of KGOWS participants reported a strong connection to Country.

"Aboriginal culture is a way of living within the environment you are born into. Learning to live in harmony with the animals, the birds, the land and the seas. Respecting the people and all that live on this earth. This is Aboriginal culture."

Terry Donovan, Gumbaynggirr/Biripi Elder and NeuRA researcher





Cultural knowledge and honouring cultural richness was described by participants in this study as an important aspect of growing old well. Elders described the need to hold on to cultural values, practices and beliefs as they age, to continue:

“Seeing through the eyes of an Aboriginal person in a white man’s world.”

(ID 205008:2-2)

Elders spoke of the connection to family and culture which is an important part of growing old well. Connections to Country and culture and maintaining family-kinship connections, as well as teaching the next generation of young people about community and Aboriginal values, were described as significant components of growing old well.

“Helping young people in regard to connection with Country and culture. I think it’s important for kids to know where they are from and how they are connected.”

(ID 504004:4-5)

As another Elder explained:

“Never to lose their culture. Be strong in a healthy way. It’s a big thing for us. It’s what I taught my girls. When they went to [the city] to live at 17 or 18 I said never forget who you are and what tribe you are from. They all remembered this and have done well.”

(ID 403018:1-4)

Furthermore, over 90% of KGOWS participants reported feeling connected to the local Aboriginal community and 2 out of every 3 participants stated that their Aboriginal culture was a great source of strength to them. Like connection to Country, a stronger connection to Aboriginal culture has been linked to significantly higher levels of self-reported health and reduced likelihood of engaging in high-risk alcohol use [8].

The painting *Waadja-da We are the Land*, by artist **Alison Williams**, a Gumbaynggirr woman, expresses these sacred cultural connections. See *painting overleaf*.



Waadjaa-da We are the Land

Alison Williams, a Gumbaynggirr woman

"This artwork speaks to connection to Country/place. Our Aboriginal Elders have knowledge and memories of ceremony and belonging to the land that span for tens of thousands of years. Stories and heritage are often orally translated according to our traditional culture.





The scar tree symbolises knowledge and way of life that is embedded in the landscape, with that, comes the use of natural resources and the transferral of knowledge and traditional practices and a continued sense of belonging. Gunyas and campsites represent living on Country.

The layers of natural materials such as stone, bark, trees and water, reflect an abundance of resources for the continuation of our way of life and Dreaming. It is the continued connection to Country that brings with it cultural education and respect for all people, and is fundamental to our survival and wellbeing."



Respect Yourself, the Elders and All the Mob

Respect for Elders and the entire mob is something that older people have learned over their lifetime, and highlight as being an essential part of growing old well.

“Respect; treat people how you want to be treated, respect others and respect yourself.”

(ID 205044:1-2)

Love, respect and compassion for others are tightly held values that Elders frequently spoke about. For Aboriginal and Torres Strait Islander peoples, the importance of interpersonal relationships and demonstrating respect has also been highlighted in terms of accessing health care services [9]. Older Aboriginal people play an important role in both caring for and passing down cultural knowledge and traditions to the younger generations. At the time of the KGOWS interview, over a quarter (28%) of participants were currently responsible for raising a grandchild or multiple grandchildren. These intergenerational connections, and having respect for and learning from Elders, are of vital importance.

“Respect for all the Elders and all the mob in [community]. I’m going to take my nephews out where I was taken. They will have a better chance of growing old well because they listen to their Elders.”

(ID 403013:5-6)

Strong supportive family relationships and nurturing friendships were also emphasised by Elders as being important for growing old well. This is also reflected in the KGOWS cohort, with 75% of participants reporting that they frequently feel useful to their friends and family, 85% reporting there was someone in their community they could trust and confide in, and almost all participants (96%) reporting that they would have someone to help them if they were sick or disabled.

“Love your family – you can’t do without your family. Keep your friends close, don’t push them away.”

(ID 202011:1-2)

Another aspect of respect described by Elders referred to self-respect and ‘living a good respectful life’ (ID 504004). Having strong cultural values, as well as living your life and making good decisions according to these values, were described by Elders as important in growing old well. The values described included honesty and telling the truth, not trying to be something you’re not, treating others the way you want to be treated, avoiding trouble with the police, choosing the right partner and rejecting domestic violence.

“Be yourself; I could have gone off the track. There’s a left track and a right track, I took the right.”

(ID 401025:1-1)

Artist, **Alison Williams**, depicts the enduring and precious knowledge of Aboriginal Elders with her painting *Jaalumbo*, submitted for this project.



Jaalumbo

Alison Williams,
a Gumbaynggirr woman

"This artwork features a midden. We on the north coast and mid north coast live in midden country. Remnants of hunting, gathering and ceremony all lie beneath the earth, like memories.

Our Aboriginal Elders have knowledge and memories much the same as a midden. Layers of stories waiting to be told and shared."





Resilience

Resilience has been recognised as contributing to the health and survival of Aboriginal and Torres Strait Islander peoples and cultures [10, 11]. Previous research has shown Aboriginal people have high levels of resilience, likely due to community-specific hardships and protective factors [12]. In particular, negative change, ill-health and racism faced by the community has been countered with protective elements including community cohesion, role-models, leadership, and sharing of knowledge, affection and culture [10].

"Resilience does not just happen, it is something that is built into you over time"

Terry Donovan, Gumbaynggirr/Biripi Elder
and NeuRA researcher, March 2019

Elders spoke fondly of the 'old days' and what it was like growing up – both the happy times and some of the challenges or hardships they faced. Elders expressed the importance of resilience and how this develops, particularly in childhood, and how this outlook is carried with you throughout your life.

"Being positive; about who they really are. Being proud of who they are. Teach this by teaching kids things I did in my childhood and how much it's changed... We had to make our own fun. We didn't know any better. To us that was the good old times."

(ID 503004:1-7)

"I learned from [my mum] how to be strong and resilient and how to face the challenges that come our way, and I think that formidability has helped me to help her at this stage of her life"

Glenny Naden, artist and carer for her mum
who is living with dementia, December 2018

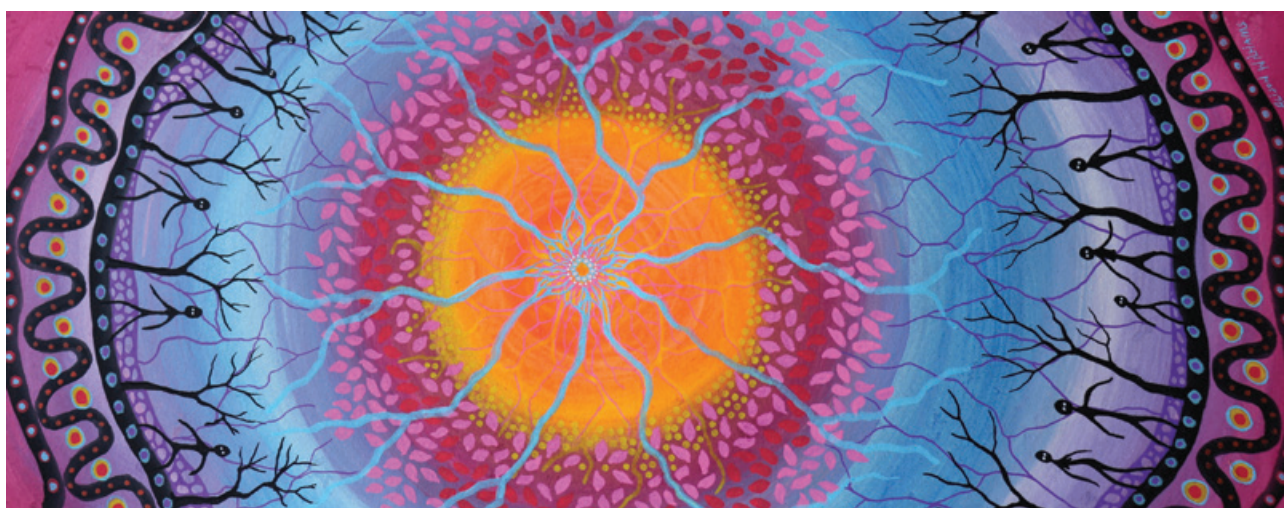
Regardless of whether resilience is viewed as a form of strength or as a necessity for Aboriginal people [11], self-perceptions of resilience appear to be an important factor for growing old well.

Indeed, KGOWS participants showed above average resilience, compared to several other international populations using the same resilience measure [13]; only older Native American indigenous peoples reported similarly high levels of resilience [14]. Moreover, in KGOWS, higher levels of resilience were associated with better self-reported health 2-3 years later [15] and were protective against cognitive decline over six years [16].

“... I’m more like – 42... I certainly don’t feel 72. And I don’t behave like it... I’m still thinking about [joining] rock-and-roll bands... So, the age thing, I guess it must literally be something that’s individual, to a certain degree. Because I know people twenty years younger than me who have given up.”

(ID 101029:17-22)

In her painting *Trek of Hope for a Dementia Cure*, Aboriginal artist Mary Jane Page depicts the ‘Eye of the Mind’ in the centre of the brain as an enduring part of an individual’s existence [17]. Using similar symbolism, **Alison Williams’** painting *As Far as the Eye Can See* also depicts the importance of memories, identity and connection to culture. See painting below.



As Far as the Eye Can See

Alison Williams, a Gumbaynggirr woman

“This artwork symbolises the electrical connections of brain matter in the format of an eye. It speaks to stimulation and identifying through vision and connection to Country.

In this artwork, the memories embedded in places and sites for Aboriginal people and Elders are represented as a reflection in the iris. The reflex memory then triggers electrical activity to the brain that ultimately unites the past and present. It is often when visiting old places from the past that memories can surface for our Elders and the sharing of story about the old days, spirituality, sacred grounds, dreamtime.”



Getting Together, Yarning, Passing on Knowledge

Elders reflected on growing older with dignity and maintaining wellbeing through getting together, yarning and, vitally, having the opportunity to pass on knowledge and life lessons to the younger generations.

"Elderly people getting together is good, yarning with other Aboriginal people, talking to other people. When you meet strangers you find out if you know them. Talk to them. Like I went to the jail not long ago and a young fellow said, 'don't I know you Aunt?' I told him his family tree."

(ID 203006:3-5)

Yarning is widely recognised as a key aspect of wellbeing in Aboriginal communities; yarning and storytelling are part of connecting people, connecting to culture and Country, and healing [18, 19].

"I always find it's healthy when you sit down and yarn with the kids and with the Elders. We get together and go to the beach."

(ID 401004:3-4)



Social connections, interactions and activities contribute to ageing well in many populations, including being associated with a lower risk of dementia [20] and mortality [21]. Similarly, social connections are likely to be protective factors linked to growing old well in Aboriginal communities. More than half (56%) of KGOWS participants reported spending time talking daily with friends or family who did not live with them, which is considerably higher than the national average of 19% [22]. Further, the majority of KGOWS participants reported almost never feeling lonely and, on average, engaging in 5-6 different types of social activities in recent months.

"Look after yourself. Participate in different things. Get your mind off your worries. Get out and enjoy people's company."

(ID 203003:1-2)

Another important aspect of growing old in good health described by participants is passing on knowledge. Indeed, three quarters of KGOWS participants said that as they grow older, they felt that it was very important to pass on personal Aboriginal knowledge to young Aboriginal people.

"Look after yourself and take in as much knowledge as you can – listen to what your Elders have to say."

(ID 501006:3-4)

Through her words and painting, artist **Juanella McKenzie**, an Adnyamathanha and Luritja woman, describes how important it is for intergenerational connections to be maintained and cherished, and for sacred knowledge to be passed on, to enable people to grow old in good health. See painting overleaf.

Core Dreaming (Strong Women Strong Future)

Juanella McKenzie, a Adnyamathanha and Luritja woman

"Our culture is ever dependent on knowledge of Elders being passed on to the next generations. This is what my painting is about. It has tiny detail, using the fine tip of a bamboo stick to dot (took forever); this piece means so much to me as it's everything that's important for us young people today and the next generation.

My painting represents the core dreaming of us all.

The Elder women sit with bowls they fill with knowledge, they share, talk, listen, learn, sing, dance, share stories and they are always together. The bowls behind the Elders represent the bowls of the future women, the girls coming up next who must fill their bowls to pass on to the next and so on and so forth. It's our jobs to ensure the bowls are filled. The lines down the bottom are a part of our body paint for ceremony, two stripes down our arm and two across our chest!"





Keeping Healthy to Live a Long Life

Aboriginal and Torres Strait Islander people are more likely to be dealing with multiple chronic conditions, both physical and mental, compared to other Australians [23]. This disparity is greatest in mid to late life and is a significant predictor of longevity [23]. Consistent with this, Elders emphasised the importance of preventing and managing chronic conditions throughout the life course.

"And as far as health and so on, I have come to a realisation that we must have a little bit more care about our health in our earlier days, because the end result is things like diabetes and the rest of it, high blood pressure and so on, which sometimes is a result of a lifestyle."

(ID 101029:4-7)

Whilst social determinants of health need to be recognised and addressed to reduce health disparities in Australia [24], Elders also spoke of taking responsibility for and being proactive about looking after their health, including regular check-ups for managing chronic conditions, preventative health checks (e.g. blood pressure, bloods, bone density, pap smears, breast self-exams, mammograms, skin checks and bowel cancer screening) and preventing chronic diseases through so-called 'lifestyle' factors like physical activity, healthy diet and maintaining a healthy weight.

"I reckon everyone over 60 should have your 715 – a full medical, every 12 months. And I honestly believe that. 'Cos you have your blood pressure taken; they do your sugar diabetes. It's all done in the one hit... more or less, you know that you're clear."

(ID 101055:14-17)

Elders' views on keeping healthy aligned with many of the guidelines and recommendations on preventing non-communicable chronic diseases, including dementia [25, 26]. Physical activity was identified as very important. Most KGOWS participants (90%) reported doing some recent mild physical activity (e.g., walking, light housework, gardening), while almost half had engaged in moderate (e.g., swimming, dancing, lawn mowing) and/or vigorous (e.g., running) physical activities in the past three months. For KGOWS participants, taking part in at least moderate physical activity was associated with a lower risk of cognitive decline or dementia over six years follow-up [4]. In addition to staying active, having a nutritious and balanced diet was raised by Elders as important for keeping healthy.

"...watching what you eat, and drink... And we try to eat well here. I mean we'll have takeaway once a week... but that's it."

(ID 101023:18-21)

Social and emotional wellbeing was recognised as another aspect of keeping healthy to live a long life. Elders spoke of the importance of communication and connecting with others, enjoying life, and looking after and making time for yourself.

"Don't bottle things up – if you need to talk to someone get it out of your system, don't carry it around with you. Talk to a close friend or someone you can trust and confide in, parents or a friend."

(ID 502004:2-4)

A holistic approach to health and growing old well was conveyed by Elders, including looking after your physical health and social and emotional wellbeing, as well as contributing to the health and wellbeing of the community.

"I've always kept myself in reasonable physical condition. Eating well. Living a good respectful life. I like to help as much as I can in the community."

(ID 504004:1-2)

In KGOWS, over two thirds of participants reported being satisfied or extremely satisfied with their life. A sense of wellbeing and satisfaction with life has been linked to increased physical exercise, reduced stress and improved cardiovascular health [27, 28]. For some people, keeping healthy involves growing, collecting or catching – and then eating – traditional foods, as depicted and described by artist **Alison Williams** in *Pippi Coast*.



Pippi Coast

Alison Williams, a Gumbaynggirr woman

"This artwork depicts women digging for pippies with their feet on the shore. An age old practice that is filled with identity and ancestry and an awareness of the rhythms of nature. Pippies are a staple food source for Gumbaynggirr and coastal Aboriginal people and are a comforting native food that evokes nostalgic memories of childhood and carefree times."

Smoking, Alcohol and Drugs

Elders spoke openly about their views on alcohol and other drugs, and expressed the importance of saying no to drugs, safe levels of alcohol use and giving up the smokes.

"Keep away from drugs, keep away from alcohol. Don't smoke. Keep a healthy lifestyle. There was no drugs when I was growing up."

(ID 401029:1-2)

Smoking: 26% of KGOWS participants reported smoking, which was somewhat lower than the national average of 31% for Aboriginal and Torres Strait Islander people aged 55+ [29]. The negative health consequences of smoking are widely recognised and significant effort has been put into smoking cessation programs by Aboriginal communities and health services. As a result, the number of Aboriginal adults who smoke has been declining. Recent data have shown that the prevalence of smoking has almost halved since 1994 [30, 31]. By giving up the smokes you can reduce your risk of many diseases, including dementia [26, 32].

Alcohol: Excessive alcohol consumption has been associated with increased risk of several chronic health conditions [33]. Notably, fewer than 10% of KGOWS participants fell into this category, and most did not drink any alcohol at all (59%) or only drank at levels considered to be 'low risk' (32%) [34]. Dementia due to alcohol abuse is rare in Aboriginal and Torres Strait Islander peoples; other causes of dementia, like Alzheimer's disease and vascular cognitive impairment, are more common [2]. Some KGOWS participants have cut down their drinking from when they were younger, but almost one third said they had never consumed alcohol.

Drugs: In KGOWS, a minority (14%) of participants reported ever using marijuana or other illicit drugs. However, many Elders expressed concerns about the problems with drug use that they have seen with younger people in their communities. Some Elders encouraged young people to make good choices and avoid drugs:

"Don't get into drugs. Don't get into the wrong company. Don't get around with the wrong people."

(ID 203003:3-3)

Other Elders acknowledged that the issues around drugs in communities go beyond individual choices and a wider community response is required to support young people, so that they have the best chance of growing old well.

"A lot of young ones are on drugs... It's a big problem. Sometimes they are surrounded by people on drugs and they have no choices other than turning to drugs. No choices, no options."

(ID 502019:6-9)



Education

Elders emphasised the value of learning and getting an education, which is also important in providing a “pathway to a good job” (ID 205008:6-6).

“I’m always preaching to [my grannies] about education. I sent them to boarding school, 12 grandchildren to boarding school in [the city]. They turned out to be state champions. They’re my champions.”

(ID 401029:7-8)

The concept of education was broad and included formal education, for example through school, workplace training and tertiary qualifications, as well as cultural education, such as learning about bush medicines and traditional languages. There was also recognition that learning and education were important across the life course.

“Lifelong learning processes – I love words. I have a project now I’m learning maths; I didn’t learn it at school... Education and language, it’s at the core of our culture. Communication, respect and understanding.”

(ID 501003:1-5)

Higher levels of formal education have been associated with a reduced risk of dementia [25], heart disease [35] and mortality [36, 37], which are just a few examples of the many positive effects of education that have been documented. Similarly, a history of skilled work is associated with a lower risk of dementia [3]. Among KGOWS participants, the majority of people completed school up to the age of 15 years and half went on to achieve some further education (e.g., trade certificate, diploma, degree or other qualification).

“I think it’s important to teach kids about the value of education. I like to go to schools and talk. Also family values – love and respect.”

(ID 504004:5-7)

In addition to formal schooling and education, cultural education plays a key role in developing strong and secure identities through passing on traditional knowledge, stories and language. Over half of KGOWS participants were told traditional stories growing up and almost half continue to share these stories with younger generations. Speaking traditional language reinforces cultural identity, confidence and fosters a sense of inclusion. Indeed, rekindling the use of traditional language has been linked to improved individual physical health and broader community health [38]. Just over a third of KGOWS participants reported that an Aboriginal language was spoken at home when they were growing up. Some Elders are actively involved in conserving traditional language in their communities and advocating for language education in local schools.

Cultural Identity, and the intrinsic link to accumulated wisdom and knowledge, are depicted by artist **Danielle Burford**, a Wiradjuri woman, in her painting 3 Turtles. See painting opposite page.



3 Turtles

Danielle Burford, a Wiradjuri woman

"3 Turtles is a tribute to one of our oldest living reptiles, the Green Sea Turtle, Elders of the sea, who carry with them the wisdom of ages. A journey of life connected to the sea and knowledge passed down through generations, as is our culture. Knowledge that reflects who we are and where we are from, travelling through many environmental changes, adapting as we go and is mostly a journey of healing.

This painting also celebrates our connection to the sea and everything it provides us, of our stories of dreamtime to our current daily events. The sea is an important part of us all, our Spirituality and Ancestry guiding us along our path."



Conclusions

Growing Old Well and Dementia Risk Reduction in Aboriginal Communities

Growing old well and reducing dementia risk often go hand in hand. As one KGOWS participant noted: “healthy ageing is your mind staying young” (ID 403002; KGOWS-I). Ageing is the number one risk factor for dementia, but dementia is not an inevitable part of ageing.

This project recognises the cultural significance and wisdom of Elders to raise awareness of dementia and promote brain health, and dementia risk reduction, across the life course.

Sharing the Wisdom of Our Elders found that older Aboriginal people emphasise cultural connections and values – including respect and resilience – as central to growing old well, along with well-established factors for health, longevity and dementia prevention.

In 2017, the Lancet Commission presented a life course model of risk factors for dementia, which indicated that 35% of dementia cases worldwide were attributable to potentially modifiable risk factors [25]. That is, it could be possible to prevent or delay the onset of dementia for many people as they grow older. The main risk factors identified were:

- **Early life:** less education
- **Midlife:** hearing loss, hypertension, obesity
- **Late life:** smoking, depression, physical inactivity, social isolation, diabetes

From KGOWS, we now have direct evidence that many of these things also increase the risk of cognitive decline and dementia in Aboriginal and Torres Strait Islander peoples. Other ‘potentially modifiable’ risk factors that appear to be important for Aboriginal and Torres Strait Islander peoples include head injury and exposure to stress and trauma, particularly in the early years of life [3, 39-41]. There is still much we do not understand about the causes of dementia, and there is currently no effective treatment or cure. However, many of the ways we look after our health and wellbeing, and live a good life, are also the ways we can reduce the risk of dementia.

Consistent with the wise words of Elders shared in this report, the 2019 World Health Organization Guidelines, ‘Risk Reduction of Cognitive Decline and Dementia’ [26] recommend:

- Physical activity
- Smoking cessation
- A healthy, balanced diet (Mediterranean-like is best)
- Reducing or ceasing harmful alcohol drinking
- Management of overweight/obesity and hypertension in midlife
- Management of diabetes

The importance of social activity, management of depression, screening for hearing loss and providing hearing aids were also recommended for their positive effects on health and wellbeing, but there is currently insufficient evidence that they reduce the risk of cognitive decline and dementia.

Importantly, the current project provides evidence of the meaning of good and healthy ageing from the perspectives of older Aboriginal and Torres Strait Islander peoples who have lived into their 60s, 70s and beyond, carrying with them vast and diverse lived experience and sacred knowledge.

This study was conducted in urban and regional NSW and does not represent all Aboriginal and Torres Strait Islander peoples. However, the participants in this study have connections to many different First Nations across Australia and, like most older Aboriginal and Torres Strait Islander people, now live in major cities or regional centres, and 'walk in two worlds'. For example, all KGOWS participants speak English and, through the impact of colonisation, relatively few have been able to hold on to their traditional languages. However, this project highlights that culture is deeply and powerfully at the centre of growing old well, and is apparent in people's beliefs, values, relationships, spirituality, sharing of knowledge, and connections to Country, ancestors, community, and younger generations.

This centrality of culture is not a novel finding; it has been widely recognised in Indigenous models of health and service delivery [42-44]. For this project, we have attempted to analyse and describe the outcomes as distinct themes, but it is clear that the picture is much more complex, with themes overlapping and intersecting. Garvey and colleagues [45], in developing a model of Indigenous wellbeing, use the analogy of weaving to describe the many elements of wellbeing and their interrelationships – the 'fabric of Indigenous wellbeing' – which defy neat categories or simple linear approaches.

The current findings contribute to and extend this understanding of wellbeing in the context of ageing, and have important implications for life course approaches to dementia risk reduction, as well as for the provision of aged care and other services to older Aboriginal and Torres Strait Islanders peoples.

"The brain is where thinking takes place, love and hatred reside, sensations become perceptions, personality is formed, memories and beliefs are held, and where decisions are made."

Professor George Paxinos [46],
Neuroscientist at NeuRA

Professor George Paxinos, Neuroscientist at NeuRA, pictured in his lab with **Aunty Margaret Anderson**, Elder, Kamilaroi woman and NeuRA researcher; and **Professor Tony Broe**, KGOWS Principal Investigator.





Ageing Well Services for Older Aboriginal People

The final aim of the *Sharing the Wisdom* project was to identify current healthy ageing programs and services and assess whether these align with the needs and expectations of the ageing Aboriginal population.

Study Design and Procedure

For this component of the project, 26 semi-structured interviews were conducted with service providers over a 6-week period in late 2018; 14 on the mid-north coast of NSW and 12 in the Sydney metropolitan area. Participating services were recruited following an initial environmental scan of services available locally to older Aboriginal people. Services were identified through our community partner organisations and networks, through accessing relevant lists/registers or community information services, extensive internet searches, and referral from other services contacted as part of this environmental scan.

The main challenges with identifying relevant services were that: some local Aboriginal community organisations did not provide specific services to Elders and felt they were not suitable for the study; some services initially identified worked to support other service providers working with older Aboriginal people rather than working directly with community members; and other services advertised programs for Aboriginal Elders on their website but, on further enquiry, we found that these programs were not (yet) available or no longer available.

Interviews were mainly conducted in person (n=24), but two were conducted over the phone for the convenience of service providers. Interviews were audio-recorded and later transcribed for analysis. The same basic guiding questions were asked of all participants (see **Appendix B**) and were around the ways in which services were contributing to healthy ageing in the local Aboriginal community, including experiences and insights into any successful approaches, as well as challenges and gaps that need to be addressed. These questions were developed collaboratively within the project team. Interviews were conducted by the following project team members: Terry Donovan, Kylie Sullivan, Alison Timbery, Madeleine Nichols and Wendy Allan.

Participating Services

All 14 services identified through the environmental scan on the mid-north coast (regional services) participated in interviews. In Sydney, 19 relevant services were identified and contacted (urban services), but 7 did not participate in interviews; 3 did not respond to contact attempts/messages, and 4 initially responded/agreed but later declined or could not be contacted again for timely interview scheduling.

The majority of participating services catered almost exclusively to Aboriginal clients and included Aboriginal health services (including Aboriginal Community Controlled Health Services, as well as Aboriginal-specific programs within mainstream health services), social and emotional wellbeing services, Aboriginal aged care, and community health promotion.



Of the 12 urban services interviewed, 7 catered entirely to Aboriginal clients.



Similarly, 9 of the 14 regional services interviewed had 100% Aboriginal clients.

Findings

There was considerable positive sentiment regarding Aboriginal-specific services, with these being described as trying to be holistic service providers for older people, often doing ‘anything needed at any point in their life really’ (ID S303). Services described how they often needed to go outside funding guidelines to meet cultural expectations, with respect for Elders being paramount. Service providers reported offering a range of different programs, often within the one service, from healthy lifestyle programs through to mental health, group activities and social outings, domestic assistance, flexible respite, financial advice, and housing referral.

“The nature of our program and services is to actually keep our Elders out of home care or aged facilities, to prolong that, and the services vary.”

(ID S402)

“We offer all of that, we offer transport, shopping, care within, you know domestic services and probably a lot of other services that are not your day to day services like, we do renal so on Saturday mornings we take our clients to [the hospital] to the renal clinic and then go back again and pick them up. And we also – if a client's in hospital and it's weekends or late at night, and they want to come home, then one of our drivers will go pick them up, so I think you have to cater for whatever comes up.”

(ID S102)

“I think it's a holistic thing but that's my point of view, because I see a bit of everything. There's housing. There's lack of transport. There's the physical, then there's the social and emotional wellbeing, like that social isolation and things like that.”

(ID S404)

These findings are consistent with the preferences of older Aboriginal and Torres Straits Islander people in the KGOWS cohort. Most KGOWS participants reported a clear preference for Aboriginal-specific aged care services (64%); whilst others were happy to use both Aboriginal controlled and mainstream services, or preferred to access only mainstream services in their local area (36%).

The importance of regular, close engagement and consultation with Elders to determine their needs and preferences in planning and delivering programs was also highlighted:

“We have community meetings so that the Elders have an input and a say of anything that they want to put up. That could be dispute, grievances or just, you know, compliments or requesting maybe looking at other activities that they want to do.”

(ID S402)

“A couple of times a year, we do run a survey to say ‘Okay, what are we doing, are we doing it right? If we’re not doing it right, you need to tell us. What are you interested in, what do you want to do, go to the movies, go to the theatre, go to art.’ ...maybe what you’re doing you need to change in some way and I think that’s all about, you know, you need to change with your client’s needs, **YOU** need to change.”

(ID S102)



“Well, I think it’s getting together for them, getting them together and talking and being active in the discussion, in improving things and what things are best for the Elders and that sort of stuff. They let us know. They’re not frightened to do that and we listen.”

(ID S301)

The need to listen to individual clients and tailor care and services appropriately was also emphasised:

“There’s huge gaps, there’s huge gaps, and I think the biggest reason for that is a lack of understanding. Whether it’s culture or location or community, I’m not sure what that is but it’s not – it’s not coming in and doing to our clients or doing to the community, it’s actually making sure that we do what they want, and I found it the same with non-Aboriginal clients, it’s the same across the board. **We’re still going in and saying this is what you need and not listening to what they actually want or need and a lot of the time, it’s just having a cup of tea.**”

(ID S403; our emphasis)

The key themes identified through these interviews are summarised and described in more detail, in the table below.

TABLE 1. Key themes identified from service provider interviews

1. Elders and Cultural Respect	2. Services	3. Needs Identified
<ul style="list-style-type: none"> Cultural obligation to care for Elders Family roles and kinship structures Understanding shame, fear and trauma 	<ul style="list-style-type: none"> Inconsistent services and funding constraints Aboriginal-specific preferred Staff who are known, trusted, and engaged with the local Aboriginal community are essential 	<ul style="list-style-type: none"> Education for families regarding ageing and dementia Education and support to access the aged care system Trauma-informed and healing-centred approaches to aged care Transport and respite for clients and their families

1. Elders and Cultural Respect

Service providers recognised the important cultural obligations associated with caring for Elders and the need to understand family roles and kinship structures, to work effectively and in a culturally responsive manner with clients, their families and their specific circumstances. As demonstrated in the quotes below, a number of service providers spoke with pride about the ways they were committed to providing culturally appropriate care and meeting the needs and expectations of Elders.

“But for us, it's really about showing the value of our Elders and our older people. And what I mean by that is, they've lived a life, they've seen and lived through some of the worst things that have happened to our people. So, how do we keep them strong as our knowledge holders and custodians?”

(ID S507)

“I hope all places are like that, I mean I think that we as Aboriginal people should be doing that for our Elders. In our communities, whether we're in medical, whether we're in aged care, whatever, your primary concern should be your patient and with us, our Elders.”

(ID S102)

“I think that we do a good job here with the Elders and as I say, they're priority, the top of the list, because we love them and because they do have their say and you've got to listen to them.”


(ID S301)

Some also noted the challenges of meeting these cultural obligations and the need for a more family-centred approach, within the current aged care system.

“And so to try and find ways that you could provide services through home care packages that understands that family, and that this is safety as well, has been really difficult.”

(ID S106-S110)

Service providers spoke of the need to understand the perspectives of Elders, and recognise the impact that feelings of shame and fear, and trauma from the past, can have on their reluctance or inability to seek out help and support when they need it.



“So, there’s a lot of stigma still around having access to doctors, and seeing anyone for help, and little other than they don’t like talking about a lot of their health or their problems, because they’ve grown up in an era, ...[it’s] always been embedded ‘don’t go talking to people about your problems, you don’t know what they will do.’”

(ID S305-S306)

“Because of experiences with the health services and in the institutions, not wanting to see doctors because of the fear of being put into residential care is really high, so we have a lot of people, Uncles and Aunties, who are experiencing what could be Alzheimer’s or dementia but don’t want to let anyone know.”

(ID S106-S110)

A related issue is the pervasive impact of trauma, and service providers explained the need to recognise and be responsive to this:

“But, when you’ve gone through that trauma, and stuff like that, the mob don’t even know how to identify how they got depression, they got anxiety, even if something’s wrong with them, they’ll keep it to themselves. If one was having chest pains issues, she probably wouldn’t even say anything, and that’s what a lot of the Aunties and Uncles do, they don’t say anything. So, that’s why the biggest thing for us as workers in the community is building that rapport, and that foundation...”

(ID S305-S306)

Service providers also described the ‘shame factor’ (ID S202) as being a barrier for Elders getting the support they need from family or through an aged care package, even when service providers were offering to provide assistance to access these supports. As one service provider observed:

“Not that it’s a problem, I shouldn’t say a problem, but there’s that factor as well... that some of our Elders don’t tell their kids what’s going on. And we can’t breach their trust or their privacy... and we wouldn’t.”

(ID S202)



Another stated:

“By the time you get a package, you’ll need it, so it’s the shame factor; they’ll say, ‘Well, I can’t do it’ or ‘Family’s going to do it’ and then family can’t do it or something happens and then they don’t get the proper package to keep that assistance going. And if they say, ‘Oh, no, I’m all good, I’m all good’ – we just found one this morning, she’s not even got a Level 1 package, and it’s like, ‘Come on, there’s nothing in that’... so I know what Auntie did, she sat there going, ‘No, I can do all that. I can do that, I’m fine with that’ – doesn’t want to tell anyone.”

(ID S203)

2. Services

The quotes below, from a range of service providers across regional and urban areas, reflect the themes related to the service environment. Meeting the needs of older people in some instances entailed providing healthy ageing education and exercise programs including aqua aerobics, falls prevention, and balance exercise programs, which were available to older people in some communities. However, these programs were described as often being ‘tacked on’ to the end of other existing programs and, for the most part, were not ongoing. This inconsistency in the programs or the lack of long term funding to keep successful programs going was one of the major gaps identified through these service provider interviews.

“One of the Elders of the first program during the last session, she said, ‘Is this going to be ongoing?’ And it’s not, that’s the problem...”


(ID S502)

Service providers spoke of the challenges adjusting to an individual consumer directed care model of service delivery, whereas previously there was more flexibility for the service to manage the funding equitably across all of their clients, according to their needs.

“You’ve got to keep your people within budget so most of ours are over budget... so I think the problem is with aged care, especially with community based organisations, is the funding. We need more money.”

(ID S102)

There was a preference for Aboriginal-specific programs and for more positions for Aboriginal workers in aged care. Service providers also expressed their views in terms of developing and valuing the aged care workforce.



"I think there should be more Aboriginal designated positions. Aboriginal people should be there delivering services to our Elders; not in every single position, but there should be more."

(ID S404)

"...it's about training people too. And about paying people what they need to be paid and not skimping because you're an aged care worker. People tend to think that aged care workers clean up after people. There's so much more that they do... so hopefully the government will see that."

(ID S102)

In general, staff who are known, trusted and engaged with Elders and the local community are needed in all types of services working with older Aboriginal and Torres Strait Islander people.

"I think that we meet the needs because, not only because we're an Aboriginal organisation, I think we've grown up, well I've grown up in this area, a lot of, all our staff live in the ... area. And I think that we provide a service that we're willing to go out of our way and we're willing to go that I suppose, past what the department requires of us."

(ID S104)

"I think that we've all got enough familiarity with all of our clients that they know us and we know them, that we can just talk to each other and sort stuff out as it's happening, if that makes sense?"

(ID S501)

Service providers also described the personal benefits of working in aged care within their communities, despite the current challenges of service delivery:

"We go home at the end of the day and we think, we may not get all these big dollars but it's the satisfaction when you walk out of here at the end of the day that someone's been picked up, taken home, they're fine and looked after."

(ID S102)

3. Needs Identified

3.1 Education for families regarding ageing and dementia

The need for education for families was identified, with lack of awareness of the main issues surrounding ageing and dementia discussed as a common gap when working with clients and their families. Education for all family members was called for, including young people, to give a better understanding of dementia in particular. Service providers explained that it is commonplace for grandchildren to be carers, with many not understanding their grandparent's needs. As one service provider explained, when speaking of current challenges:

"I feel education for the young people. They don't seem to understand if a person - like my mum always says, 'Did I take my tablets today?' She might say that every five minutes. And I'm like 'yeah you did'. And then the kids will say, 'I'm sick of Nan saying that all the time.' And my nieces and nephews live there in the house with her. Yeah, it's education."

(ID S201)

However, education is required for everybody, not only for young people, particularly to support families to take care of Elders living with dementia in their home. As another service provider explained:

"We certainly have a fair few Elders that their family just don't have a general good understanding of why their moods might have changed or why all of a sudden they've forgotten where they are, so, you know, a lot of that preventative stuff you can put in place for the family. We sort of always - that gets missed and we only get it at crisis stage, 'cos the family just don't understand, so you won't see Nan or Pop for a couple of months 'cos the family will stop taking them out right up to the point where it just gets too hard for them to even look after Nan or Pop, and then we hear on the grapevine, or another community member generally tells us, 'Hey, listen, Aunt's not eating, we're worried about her', you know, and we always act, but family - it would be great to have some really great basic education for the family."

(ID S202)

3.2 Education and support to access the aged care system

Significant challenges are experienced by Aboriginal and Torres Strait Islander people in both understanding and accessing the current My Aged Care system. It was described as difficult to navigate, with the need for more information about aged care packages required. Better information and support is needed for prospective clients and their family carers, as well as for service providers working closely with Aboriginal and Torres Strait Islander communities. The same issues were expressed relating to the NDIS, hence:

“There’s that barrier, that’s what it is, mob needs to get connected with NDIS, and say ‘Hey, you mob this is here for all of the rest of Australia, why can’t you just get out here and just inform us a bit more so we can help our community?’”

(ID S305-S306)

“The whole structure of aged care now, it’s confusing and it’s frustrating. I find it hard to follow and understand because there’s so many changes, and I’ve been in this job for eight years and I still find it confusing and it’s hard to understand, so I can’t imagine how our Elders deal with that.”

(ID S404)

“...there are so many programs that are needed that fall out of that specific home care package approach and so trying to find someone who understands why collective healing is important and what a gathering is and that it is not just a reunion [is a challenge].”

(ID S106-S110)

3.3 Trauma-informed and healing-centred approaches to aged care services

As discussed above, trauma is a significant issue for many older Aboriginal people and their communities, which needs to be acknowledged and addressed through trauma-informed and healing-centred approaches to aged care. Moreover, this can only be achieved through culturally responsive services. A lack of sufficient knowledge or understanding of cultural protocols and Elders’ past experiences by mainstream services was raised; greater knowledge and understanding are required, at a minimum, to foster a healing and empowering approach.



“Mental health, mental health is big thing a lot of our Elders are depressed with whatever things, some of them die of a broken heart, and of broken spirits, when I think about it. There’s a lot of that, I think, I’ve never met an Aboriginal person that has not been affected, or has had family affected by colonisation, and the trauma that’s been passed on.”

(ID S305-S306)

“We have an aged care partner who has assisted some of the [Elders] with home care packages and we find the system very challenging and definitely it is not trauma-informed. It doesn’t especially understand Stolen Generations’ experiences and why ageing is so critical to do well, and also hasn’t empowered the families to look after their Elders and support them during the ageing experience and dementia has been a real issue for a lot of the [Elders].”

(ID S106-S110)

3.4 Transport and respite for clients and their families

In several areas, transport was identified as an issue for people who want to use a particular service, such as an Aboriginal-specific service. In both regional and urban settings, older people often have to travel; however, transport is not always available or, if it is available, can often be costly or is not accessible for ageing people living with disability, including physical frailty or dementia. The need for transport for family or other community members to visit older Aboriginal and Torres Strait Islander clients, to maintain social and cultural connections, was a related issue. As one service provider explained:

“...in our organisation we are not funded for transport. So how you would get a group of people to go visit on a regular basis is a challenge.”

(ID S106-S110)

Culturally specific respite and spaces or support networks for family carers were needs that were also identified. As one service provider noted, “...we’ve got carers who are screaming out for respite” (ID S507). Recommendations included that carers should have access to a culturally appropriate caring space, as well as respite, that would enhance socialisation and provide opportunity for rest, recreation and cultural connection, to maintain carer wellbeing.

Recommendations for Ageing Well Services

The following recommendations (in no specific order) are made to support service providers and policy makers in addressing the challenges identified through interviews undertaken for this report.

- i) **Supporting Elders:** The important role of Elders is recognised. There is a need to prioritise the support of Elders in meeting their health needs, which often become different as they age. Elders need to be consulted regularly regarding their changing needs and preferences, and services adapted accordingly. This also requires a localised, community-driven response to service planning and delivery.
- ii) **Review of existing services and information:** A scoping study of existing information related to Aboriginal and Torres Strait Islander aged care needs is recommended. It is recommended that a plan be established to map the existing information services to Aboriginal-specific care services and to better implement aged care and dementia education in Aboriginal and Torres Strait Islander communities. Education for service providers is also needed.
- iii) **Innovation, creativity and co-design of services:** The wisdom and knowledge of older Aboriginal and Torres Strait Islander peoples, combined with the importance for Elders of passing on their cultural knowledge to young people, can provide opportunities to design healthy ageing programs and aged care services which incorporate intergenerational links, activities and engagement, and strengthen cultural connections to benefit young and old. We encountered some positive examples through this study, but this approach could be more widespread and the benefits acknowledged through funding support for such initiatives.
- iv) **An Ageing Well Hub:** It is recommended that communities give consideration to establishing an Aboriginal and Torres Strait Islander Ageing Well Hub/Yarning Place. This centre would be a one stop shop for information, referral, and a place of support, which could be embedded within existing Aboriginal community controlled services.

These recommendations reflect the insights presented to us by participating service providers whilst also seeking to support the values and wishes of Elders who participated in the KGOWS research projects. In fulfilling these recommendations it is hoped that more effective models of service delivery and health promotion will be developed as well as creating opportunities to foster new support networks for older Aboriginal and Torres Strait Islander people, their families and carers.



Reflections of the Research Team

Towards the end of this project, research assistants from *Sharing the Wisdom of Our Elders* reflected on their experiences. These researchers played key roles throughout the project in terms of community engagement, recruitment, interviewing, data analysis and interpretation, selecting artworks and designing resources, and sharing the project findings back to communities. The various individual reflections from each of the project team members are presented below, in no particular order.

- It was paramount that we did this in a very respectful and culturally safe way. I felt that my position in the team was to give the team a perspective on cultural awareness to facilitate appropriate communication with our Elders. Importantly it had the Elders feeling safe and at ease during our time with them.
- The project gave me a better understanding of what's out there to help the Elders in their communities, whether it was a group they visited for a shorter amount of time or a company trying to help.
- While conducting the interviews, it was great to see so many excellent services already available in the community, however, many of the same challenges kept being identified. This has shown some clear obstacles to providing effective services that cater to Aboriginal Elders that need to be addressed.
- The Interviews were a crucial part of the project, to enable us, as researchers to help identify all the positives and negatives of what was, and was not working in their services, to gain insight from them of the many needs of our Elders that required addressing to promote and enhance the quality of their lives.
- After the interviews I was impressed with some of the companies and services that are out there that help with the needs of our Elders. Sometimes I left wanting to help.
- My initial thoughts about the interviews were that of trepidation for I thought that the questions were intrusive and that as a people we had had enough of giving for no reciprocation, in the way of better facilities such as services that would lead to independence. I also thought that the questions would show our people in an unfavourable light. After the interviews I now look upon the *Sharing the Wisdom of Our Elders* project as a way of benefiting our people, especially with the suffering that we endured most of our lives with all the chronic diseases. I now see that the programs we have developed as a team will in time enhance and encourage change. I also reflected on the way our participants reacted, each of the participants were willing to engage and ask questions about the program, each gave their time willingly and answered all questions freely.
- Overall I think this project is an excellent way for our Elders to tell us in their words what does growing old well mean to them. It also has highlighted the lack of mainstream services that are available for our people. The work we do in our communities gives us a better understanding of the risk and protective factors for dementia.
- This project has facilitated community feedback and engagement in a number of ways, both steering future research and contributing to healthy ageing and dementia prevention resources. I believe this project has been extremely positive, giving voice to our community members to tell us "what is good and healthy ageing?" to them.

- As the project is in the final stages I reflect on the knowledge that I have gained whilst working with all our team members and the way each of us conducted ourselves in a culturally appropriate and respectful way while working with our people and in our communities. It has been very difficult for health services to understand in the past the reasons why our people would not go to health services. The reasons are numerous, not trusting mainstream services to taking care of family first, as a research institute NeuRA's research in the dementia field has in my opinion helped to change attitudes to understand that our health is important if we are going to be around for our families, and we look to where the results of the project will be in the future.
- I find the final stages of the project quite an exciting phase, as we can all come together to go over our findings to help identify the most important requirements that are needed to enable and empower our Elders to live happier, fulfilling longer lives, so that we can participate in recommendations to assist service providers in incorporating successful, culturally appropriate programs and activities for not only the Elders, but for the carers and families of people living with dementia, such as much needed respite and education about the condition.
- I'm glad that this project was carried out as I hope that it can help to inform ageing policy and improve service provision in the community both by highlighting the strengths of existing services as well as the gaps.
- I would love to be able to promote some of the excellent services and people that we have had the privilege of interviewing and provide a platform to showcase the ways in which people have grown old well in their own ways and the response to this through art.
- Overall, I think this project was extremely rewarding; to be out in the field, meeting with all of our service providers and capturing all their feedback on the programs they offered, the gaps they identified in service provision and some of the many challenges they came up against trying to incorporate viable, culturally respectful, ongoing programs and activities for our Elders.

Sharing the Wisdom of Our Elders Research Team


L-R Alison Timbery, Kylie Sullivan, Terrence Donovan, Margaret Anderson. Madeleine Nichols (not pictured).



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Appendices

APPENDIX A

Call for Artwork

APPENDIX B

Service Provider Interview Guide

APPENDIX A

Call for Artwork

Sharing the Wisdom of Our Elders – Understanding and promoting healthy ageing with older Aboriginal Australians

Art – Project Outline and Artist Brief

Neuroscience Research Australia (NeuRA) is an independent, not-for-profit research institute based in Sydney. Researchers from The Aboriginal Health and Ageing Program at NeuRA have worked in partnership with 5 Aboriginal communities in NSW since 2008 – Coffs Harbour, Nambucca Heads, Kempsey, La Perouse and Campbelltown. The Koori Growing Old Well Study (KGOWS) is a population-based study of ageing and dementia with 336 Aboriginal and Torres Strait Islander Australians aged 60+ from urban and rural areas of NSW (Radford et al., 2015); with major dementia findings consistent with other research in remote WA and NT (Li et al., 2014; Smith et al., 2008). However, the majority of KGOWS participants (approx. 2/3) did not have any evidence of cognitive decline and are ageing well.

This project, *Sharing the Wisdom of Our Elders* is in response to research highlighting limited awareness of ageing and dementia across Aboriginal community members (Garvey et al., 2011) and requests from KGOWS partner communities for a strengths-focused Aboriginal specific teaching resource to increase community knowledge of dementia prevention which we have shown is 3 times more common in older Aboriginal people and likely linked to preventable risk factors from early life onward (e.g., Radford et al., 2017).

Sharing the Wisdom of Our Elders project acknowledges the central role that Elders have in the Health and Wellbeing of Aboriginal Communities and the role that art has in representing their stories and traditions.

Background

The importance of culture and Elders stories that explore the meaning of healthy ageing from Aboriginal people themselves have been documented in the research questions in the Koori Growing Old Well Study (KGOWS-I and KGOWS-II 2008-2018). *Sharing the Wisdom of Our Elders* is a project funded by the Lowitja Institute (2018-2019). The project focuses on the theme of Strong Elders and what is good and healthy ageing for Aboriginal and Torres Strait Islander people. In KGOWS, the same open-ended question was asked of all participants: *Over your lifetime, what have you learnt is important for growing old well?* This project will represent the responses of Elders in artwork and stories.

Artist Brief

To assist in achieving our aims the project team are inviting Aboriginal artists to submit works that identify with the themes of our project – refer to **Figure 1.0** and **Table 1.0**. We invite artists who are descendants of the Aboriginal Nations of NSW to submit works of art or concept designs that relate to our themes.

We are looking for 8 or more works for our project that relate to the themes of our project as described in the table and diagram below. Artworks will be professionally photographed, and a licencing agreement with exclusive copyright for a fixed term will be negotiated with successful artists. Acquisitions of works deemed suitable by the selection committee are also a possibility.

Successful artworks will be incorporated into a range of Aboriginal specific healthy ageing/health promotion resources which will include but are not limited to books, posters, in hard copy and on-line format as well as Ageing Well conference posters and presentations.

This represents an opportunity for enhancing the profile of individual artists used with dissemination of resources to a broad range of community groups as well as health related academic audiences.

Payment of \$500 per artwork chosen to be photographed and used. Payment for acquisitions will be negotiated in accordance with NAVA rates of pay (National Association of Visual Arts).

NEURA will respect the artists' intellectual property rights and a formal agreement will also be negotiated with the successful artists.

FIGURE 1: Overarching the Themes

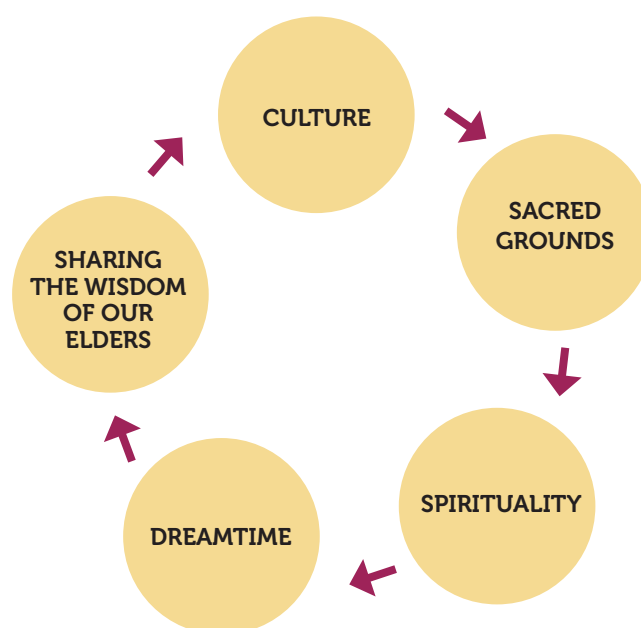


TABLE 1.0: THEMES

CULTURE – SACRED GROUNDS – SPIRITUALITY – DREAMTIME

CULTURE	RESPECT FOR ALL THE ELDERS AND ALL THE MOB	GROWING OLD IN GOOD HEALTH	KEEPING HEALTHY STAYING HEALTHY TO LIVE A LONG LIFE	EDUCATION	LIVING A GOOD RESPECTFUL LIFE	THE OLD DAYS	DRUGS AND ALCOHOL
Connection to family Family – Kinship connections	Family Values Love and Respect	Growing Old Gracefully – <i>Your Supposed to</i>	Whole of life approach to health <ul style="list-style-type: none"> Physical Health Mental Wellbeing Eating Well – Nutritious Foods 	Formal and Cultural Learning	Honesty Telling the truth Not trying to be something you're not	Resilience	Saying <i>No</i> to drugs, alcohol and giving up the smokes
Connection to community	Values of Elders	Dignity	Wellbeing Health Checks – Managing Chronic Diseases and Health Prevention Preventative Health e.g. <ul style="list-style-type: none"> Check-ups, BP, Bloods Bone Density Pap Smears Breast Self-Examinations Mammograms Skin Checks 	Bush Medicines	Treat others the way you want to be treated	What it was like for you growing up	Safe Levels of Drinking
Love and respect	Self-Respect		Mental Wellbeing <ul style="list-style-type: none"> Communication Look after yourself Enjoy Life Time for yourself Connect with others 	School Education Work	Say no to Domestic Violence	Happy Times	
Connection to Country	Respect others				Say no to Police Interventions		
Connection to Community	Nurture Friendships				Choosing the right partner		

APPENDIX B

Service Provider Interview Guide

Sharing the Wisdom of Our Elders – Understanding and promoting healthy ageing with older Aboriginal Australians

Participant ID:

Interview date: //

Interviewer initials:

Please remember that all information collected will be kept strictly confidential. No identifying features will be used in any report associated with the project. No individual information will be released to any person or department except at your written request and on your authorisation.

Please tick the response.

Are you male or female?

☐ Male ☐ Female

How old are you?

☐ 18-25 ☐ 25-34 ☐ 35-44 ☐ 45-54 ☐ 55-64 ☐ 65+

Are you Aboriginal or Torres Strait Islander person?

☐ Yes, Aboriginal ☐ Yes, Torres Strait Islander

☐ Yes, both Aboriginal and Torres Strait Islander ☐ No

1. How would you describe the nature of the services or programs that you and your organisation provide to older people?
2. Approximately what proportion of your services/programs is focused on older Aboriginal and Torres Strait Islander people?


2.1 How many Aboriginal and Torres Strait Islander clients do you have?

3. Does this include an exercise program?

☐ Yes ☐ No

If yes, please consider the following specific questions:

- 3.1 Who is delivering the exercise classes? (i.e. the background of the provider). Examples include Aboriginal Health Worker, Tai Chi Leader, Nurse, Physiotherapist, Occupational Therapist, Sports



Teacher, Exercise Physiologist, registered Local Health District Physical Activity Volunteer, Fitness Leader – Cert III, Fitness Leader – Cert IV, Fitness Leader – Registered, Fitness Leader – Accredited, Registered Yoga Instructor, Dance Instructor, etc.)

3.2 What types of exercise are included? (e.g. balance, strength, aerobic, seated versus standing, aqua)

3.3 How long does a class go for? And how much of the class includes balance and/or strength exercises? (Estimate % time allocated to balance and/or strength exercises)

3.4 Where is the class delivered?

3.5 How many people are in the class? Are there regulars? Do new people join?

3.6 Is there transport provided?

4. What do you see as the main health concerns for older Aboriginal and Torres Strait Islander people in this community?
5. In what ways does your service/program address (or aim to address) these concerns?
6. In your opinion, how well does your service/program meet the needs of older Aboriginal and Torres Strait Islander people in this community? And why?
7. Can you give some examples of the things your service does well in meeting the needs of older Aboriginal and Torres Strait Islander people?
8. What are the main challenges you have experienced in delivering services/programs to the local Aboriginal community?
9. How could healthy ageing services and programs for older Aboriginal and Torres Strait Islander people be improved? Are there any gaps that you have identified?
10. Is there anything else you would like to add?

"Aboriginal culture is a way of living within the environment you are born into. Learning to live in harmony with the animals, the birds, the land and the seas. Respecting the people and all that live on this earth. This is Aboriginal culture."

Terry Donovan, Gumbaynggirr/Biripi Elder
and NeuRA researcher





How to Access Project Resources

Links to video resources and PDF downloads:

www.neura.edu.au/sharingthewisdom

Or please contact:

NeuRA Aboriginal Health & Ageing Program

Email: AboriginalAgeing@neura.edu.au

Phone: (02) 9399 1269

Contact Details

Aboriginal Health & Ageing Program

Neuroscience Research Australia (NeuRA)

139 Barker Street (PO Box 1165)

Randwick NSW 2031

Email: AboriginalAgeing@neura.edu.au

Phone: (02) 9399 1269