



Healthy Ageing in Aged Care Study

Community Report: Stage One

Why this research is important

Aboriginal and Torres Strait Islander peoples are living longer and, by 2031, the number of people aged 65 years and over is anticipated to double. This growth in the older Aboriginal and Torres Strait Islander population will result in a greater number of people needing to access culturally appropriate and quality aged care services. These services are required to support people to age well, maintain independence and meet cultural needs in ways that are defined by Aboriginal and Torres Strait Islander peoples themselves. Some challenges experienced by Aboriginal and Torres Strait Islander peoples and their families as they investigate options for aged care include accessing culturally safe assessments, confusing processes for using the My Aged Care system and a lack of choice of aged care providers.

Research Aims

The Healthy Ageing in Aged Care Study aims to understand how the aged care system can best support older Aboriginal and Torres Strait Islander peoples across South Australia. Together with communities and services we aim to co-design improvements that will support healthy ageing. This research comprises three stages. Stage One which involved interviews with people receiving aged care services and their family members is currently complete.



The co-design process throughout the three stages of the research aims to help Aboriginal communities, aged care services and governments to work out the best way to support the health and wellbeing of Aboriginal and Torres Strait Islander peoples receiving services at home or in a residential facility.

The following information in this *Community Report* describes how we have collected community perspectives for Stage One. This includes what we heard, what the stories are saying about aged care and how we will integrate the key messages from the stories into the next stages of the research.

Stage One Approach

An Advisory Group of Aboriginal community, health and aged care stakeholder representatives was formed to guide the Stage One activities of the research. Together, the Advisory Group and the researchers engaged with Aboriginal Community Controlled Health Organisations (ACCHOs), Aboriginal Community Controlled Organisations (ACCOs) and an Aboriginal controlled aged care organisation to find older Aboriginal community members to participate in the study. With their assistance, we were introduced to older Aboriginal people receiving aged care services through the Commonwealth Home Support Programme (CHSP), Home Care Package (HCP) Program, or living in a residential aged care facility.

We interviewed 61 older Aboriginal and/or Torres Strait Islander community members who were receiving care and their family members.

- 49 (80%) were receiving aged care services;
 - 23 of these were receiving aged care services care at home through the Homecare Package (HCP) Program
 - 11 were supported through the Commonwealth Home Support Programme (CHSP),
 - 7 were in residential care facilities
- 12 (20%) of interviewees were family or friends of the older person receiving services.
- The older people were aged between 52 to 87 years, with most aged 71 to 80 years.
- There were similar numbers of interviews across the study locations.
- More women agreed to participate than men (44 women vs 17 men).

In total, researchers Ms Treena Clark, an Aboriginal researcher of Kokatha and Wirangu descent and Dr. Adriana Parrella, a non-Aboriginal researcher, conducted 40 interviews. We conducted the interviews face to face, in peoples' homes, or at their ACCHO or other public places across South Australia. We developed the interview questions with the guidance of the Advisory Group. The interviews were informal to encourage yarning between the people being interviewed and the researchers and ranged from 20 minutes to 1.5 hours.

In the interviews we asked people to talk about:

- The aged care services they are receiving and how they feel about them
- Their everyday life and activities as Aboriginal people receiving aged care services
- Their thoughts and beliefs on health, getting older and keeping well

The interviews were recorded (with permission) and transcribed. The interview team and Ms Ashleigh Morrison, an Aboriginal researcher of Jawoyn and Dagoman descent, analysed the data. Analysis and interpretation of this data was completed with the support and guidance of the chief investigators of this study and study advisory group members.

Stage One: What we learned

The interviews with the older people and their families provided insight into Aboriginal and Torres Strait Islander peoples' concepts and experiences of health, ageing well and how they felt about their current aged care services.

The older people identified many areas of strength that helped them age well. These included access to Country, having a sense of humour, positive attitude, strong family supports and being assisted to maintain their roles within their family and community. We heard from one older person that being on **Country** helps her heal when she is feeling sick.

"I love it in [town name redacted]. Like it's my home. I can just go [name redacted] where I was born and if I feel down and depressed, I can just take my shoes off and put my feet in the ground. So that's what I do."

Many of the older people identified **sharing stories** about their legacies, for example, of their working lives in younger years, as key motivators in **maintaining their identity**, role and **contribution to their communities**.

"We actually worked for our communities. Our people... We all worked in Aboriginal organisations. Worked with Aboriginal people."

They also communicated that maintaining **positive family connections**, taking care of family, and **relying on family supports** were pivotal to achieving and maintaining their health as they age.

"I'm quite contented. I've got my grandkids there. Now I've got the two great-grandchildren and they come down and see me. My grandson, he's 13 now. God they grow up so quick. As I said, he just lives up two houses and he's a big help to me"

"Because it's got a lot to with strengthening your bones, mind, body, soul – everything. Everything, to keep that body health because you're here for your family, and a mother is a mother, and a mother is the backbone of the family. She has to keep herself healthy to be here for her children because no-one will love their children the way a mother does."

Having a good sense of **humour** and a **positive outlook** helped people 'age well'. Acceptance of their health conditions and stage of life, combined with the ability to reflect and make jokes about their circumstances, helped people cope with the difficulties associated with ageing and allowed them to maintain their **emotional and social wellbeing**.

"So, I don't worry about it. I just get on with it and get on with my life, you know. Be happy and get on with it [laughs]. Be happy, yeah. That's the best thing to do, really. There's nothing much you can do. Otherwise, you'd be crying all the time. So, I don't want to cry, so I just thought, well, just get on with what I have to do, and that's it."

"We have a little joke sometimes. I'll say, well, when I get older, I said, you're going to have wipe my bum."

Aboriginal and Torres Strait Islander concepts of health are holistic and not merely an absence of disease. Aboriginal and Torres Strait Islander concepts of health encompass culture, country, spiritual, social and emotional wellbeing. When asked about their health, many people talked about chronic disease (kidney, heart, arthritis and diabetes) and experiences of other conditions such as cancer and stroke. They perceived chronic disease

and other medical issues as a fact of life or simply a thing that existed for people. Although for some people the effect of ill-health impacted their outlook on life and health at times, most people accepted problems with their physical health as part of getting older. However, when people reflected on their life stories or their care arrangements, the effect of ill-health at times disrupted their ability to engage in social and cultural activities. The main sources of enjoyment and wellbeing, or conversely of disappointment, for the older people were in the amount of culturally relevant social opportunities they had, as well as their ability to maintain cultural connectedness.

When discussing health and social supports, to the older people clearly preferred to **access these through their ACCHOs and local ACCOs** and they valued these organisations highly. ACCHOs and ACCOs assisted people in maintaining their cultural connections and fostering their Aboriginal identity within their respective communities.

“Oh, it makes us feel good. It makes me feel good. It’s just that respect. There is a lot of respect in the community - I guess, in all places, aye? Because with our little ones knowing who their older people and their aunties and uncles, no matter who they are or where they come from”.

Additionally, the older people identified **Aboriginal-specific social groups and gatherings** as important to many of the older people.

“That’s been going for years and it’s only been the last few years that I’ve actually joined because I’d never heard of them, right? My cousin... she just lived across the road from me. We hardly see each other but once she said to me, oh, there’s an Elders group we’ve got up here. Come and see. That was the best thing I ever done because ... I could meet up with other black fellas and have a good yarn and share and that’s what’s kept me sane too.”

Our informants shared many stories about **getting older** and what was important to them. Some people described ageing as a privilege and emphasised the importance of self-care.

“I love it, yeah. I love getting old. I don’t feel - a lot of people think, oh, I don’t want to be old. But I like it. I think this is something that - it’s new [laughs]. Well, it is new, isn’t it? Every year, something new is coming. Every - something’s coming, and you think, well - you know? Yeah. So that’s what I look forward to. I think, well I’m hoping to get to 90, in my 90s [laughs], and to get there. So, thinking I’ve got to - you know, got to look after myself”.

One male told us about the importance of taking care of yourself as you get older:

“When you start getting older everything starts to not work as it should do. And then, yeah, your body starts telling you stuff and you know your limits. Yeah, so you need to start taking care of yourself.”

Although, overwhelmingly, the older people wanted to **maintain their independence** for as long as possible, some people anticipated higher care needs into the future. Many of the older people expressed a desire to hold off on applying for higher levels of aged care assistance because they wanted to continue to do things for themselves, and they believed this was a good way to maintain their autonomy.

“Yeah, because I’m an independent person, and I don’t want my independence taken totally away.”

In addition to these strength-based perspectives on ageing well and concepts of health that older people shared in the interviews, we also heard about complex social and environmental issues that impact on their ability to age well. Aboriginal and Torres Strait Islander peoples are eligible to receive aged care services from the age of 50 years. This means that services need to cater for a broad array of needs and circumstances across the different ages of this older population. The increased experience of chronic disease and disability, as well as the intricate kinship caring arrangements, result in a diversity of support needs for this group of people.

Many of the older people in this study were both receiving family support to help with daily living and providing high levels of support to family. For example, some people we interviewed were still raising young children, caring for grandchildren or supporting more incapacitated family members. Many were struggling with **basic needs like income, housing, safety** and the difficulties of living on welfare payments.

One person shared with us her difficulty surviving on Centrelink payments. Without adequate **financial support** this person could not afford internet access and as a result it impacted on her ability to access an online health program as recommended by her doctor. At the same time, her request to include the cost of this as part of her Homecare Package had been rejected by her care coordinator. This is occurring in an older person's life at the same time her autonomy and physical mobility was declining.

"I could only afford \$30 a fortnight out of my dole for my little internet modem little thing I plug in; I can't get on the internet for too long, because I use it very quickly."

Future planning is a source of anxiety for people, whether they are considering more home-based aged care services, future residential care or budgeting for funeral costs. A female participant on a HCP told us:

"Well, when you get older and you think about what you're - where you're going to end up, when you're really sick or you've got dementia, or that sort of thing, or - would you go into care home, and that's going to cost heaps and heaps of money, and because I'm only on a pension."

Positive family support is a major protective factor for older people. Less supportive family situations can result in significant stress and leave older people feeling vulnerable. One participant shared with us difficulties he was experiencing with lack of support from some family members.

"I've been thinking about getting a medical alert thing...because I live by myself. In case I do have a heart attack because I've got heart problems and that because I don't get no visitors. Maybe my brother will ring me up."

The changes people want in aged care

The key things older people wanted from their aged care were:

- More organised culturally specific social groups;
- Better and consistent communication from their providers and clarity on their entitlements;
- Homecare Package services that meet the unique cultural needs of Aboriginal and Torres Strait Islander peoples, for example long-distance travel for medical appointments and travel for Sorry Business;
- Autonomy and real choice; and
- Culturally safe workforce.

We heard that many social groups and outings have ceased due to Covid-19 and sometimes because of organisations' lack of funding. These culturally specific (Aboriginal only) social programs have been a highlight for many of the older people, and their cessation has undoubtedly had a negative impact. Many of the older people used these groups for socialising, maintaining relations, and staying connected to culture.

"Yeah, before the funding stopped. Then we used to go and collect bush medicine and all that, have a day out, maybe a barbie and that."

These **social groups have been important for the health and wellbeing** of older people.

"I would like for myself and my mental health and everything else, I would like to start up or be involved in a yarning session about old times, about me as a child, my grandmother, things that she taught me."

These social groups and the activities provided are particularly important for people who reside outside of major metropolitan areas.

"You've got the footy, you go to the footy, that's about it. I don't know about anything else. Really, you've got to make your own entertainment. In Adelaide you can go anywhere you want in the town centre. You make your own enjoyment, you know what I mean? Go out and have a few, have a drink and socialise that way. That's the only entertainment or it's just the pokies."

We were told that lack of clarity around their entitlements (including costs that clients were charged) and poor communication with their aged care coordinator was a common experience. We heard about some of the ways older people wanted **better communication with their aged care coordinator**.

"I said look here, can you do this for me? I told her to get something. She never rang me back...Like she's got too much on her plate like. I don't know. When I get that worked up I go straight to see her. Talk to her face to face. I don't like talking on the phone."

The older people told us they also want **increased flexibility and culturally safe options** as part of their aged care service. Some people were unable to use their aged care financial support to carry out culturally specific obligations. Greater flexibility on how this funding can be used would be extremely beneficial to the health and wellbeing of older people, particularly in supporting them to fulfill cultural obligations like Sorry Business.

"I don't have the time to ring [not-for-profit] or [not-for-profit] to try - or here [ACCHO], they don't do fuel vouchers here, to try and find a fuel - somewhere that would help to

get - it would be good if there could be money out of my package to be put aside, a couple of hundred dollars, two or three hundred dollars so that I can actually go to [location] or [location] to attend a relative's funeral."

Similarly, increased **flexibility in how funding can be used** would be extremely beneficial to many older people, particularly those in regional and remote areas. Funding travel and accommodation for specialist medical appointments was extremely problematic for many older people.

"I've got to be there overnight, pay for my accommodation. They say, sorry, but we can't. They can understand that when you're ageing, a lot of...a lot of health issues are going to – you know. The majority of the services aren't available in [town]."

Many of the older people felt limited in their choices when it came to their aged care services. This affected all aspects of the services, including lack of choice in service providers, home care package services and items, and when or how they received these services.

"I had to get to and clean up that mess myself, almost wipe myself out because this person can't come until Thursday because they've got these people on Monday and then these people on Tuesday. That I don't like because it's about choice. That's not choice if you're being told what day you have them and how long you're having. That's not choice."

Overall, people wanted to be able to exercise **greater choice** needs.

"By them being very understanding and know the wants and needs of people and meet their needs and remember it's not their money. You know it's not how – so it was given by the government, give it to us in the right way, and help us to get the things we need so that we can better our lives."

We heard that culturally safe aged care staff are critical to a positive experience of services. People commonly stated they preferred an Aboriginal care worker. However, when this was not possible, we heard that non-Aboriginal workers need to have **cultural understanding**. The son of an older person receiving aged care services told us:

"But as [name] rightly said, for mum, we need those services and we need them now, but we need compassion, we need Aboriginal workers to actually show the way and way forward and if we haven't got Aboriginal workers, then we need the workers that are currently doing the job to be proactive in learning how to engage."

What we will do next

The findings from Stage One will be shared with the communities and organisations involved in this research. Key organisation contacts that have been identified through Stage One activities will be contacted in addition to other aged care, health and community organisations in preparation for Stage Two. Stage Two will involve interviews with representatives of aged care and other organisations. The interviews will provide an opportunity to respond to the findings of Stage One. Feedback sessions with communities will include opportunities to assist in the development of the interview questions for Stage Two.

Thank you

We wish to thank all study participants for their generous contribution and time in sharing their stories with us.

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