



Stakeholder Feedback Report

November 2024



**Let's CHAT (Community Health Approaches To)
Dementia in Aboriginal and Torres Strait Islander
Communities Project**

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1. Overview

The Let's CHAT (Community Health Approaches To) Dementia in Aboriginal and Torres Strait Islander Communities was a co-designed research project with 12 co-researching Aboriginal Community-Controlled Health Organisation (ACCHO) partners nationally. The project developed a best-practice model of care aiming to increase detection rates of cognitive impairment and dementia of Aboriginal and Torres Strait Islander clients attending ACCHOs, and to optimise the management of these conditions. Working collaboratively, the Let's CHAT research team and research partners developed a culturally relevant best-practice guide and developed and implemented an education program, resources and strategies to embed best-practice dementia care principles into everyday practice in primary care.

The study aimed to address the known low detection rates of cognitive impairment and dementia in primary care, and high prevalence of these conditions across Aboriginal and Torres Strait Islander Communities in Australia.

The Let's CHAT Dementia study ran from 2018, throughout the COVID pandemic and concluded implementation and data collection in 2023. Subsequent statistical analysis of the data has shown that while the intervention groups did not show a statistically significant difference from the control groups in terms of increasing detection rates of cognitive impairment and dementia, the intervention *did* improve management of dementia detection. To understand management, we investigated uptake of the diagnostic pathway for cognitive impairment and dementia by noting instances of concerns being raised about cognition (by the client, a member of the health care team or other) coupled with evidence of follow-up activities. The criteria were documentation in the client's medical record of *at least two* of the following:

- Cognitive assessment;
- Relevant pathology investigations;
- Relevant neuroimaging (CT or MRI);
- Referral to a memory clinic/geriatrician.

Uptake of the diagnostic pathway increased more than twofold during the intervention phase, indicating a clear effect from the Let's CHAT program. Further detail on the Let's CHAT Study is presented in Appendix A.

As part of the dissemination work for the project, roundtable events were hosted in Sydney (September 2023), Perth (September 2023) and Melbourne (June 2024). In addition, the Let's CHAT Lead Investigator, Project Manager and Kimberley Research Officer hosted/participated in a series of meetings with different stakeholder groups in the Kimberley in August 2024. A diverse mix of **stakeholders** involved with First Nations health and/or dementia took part in the roundtables (n=79) and Kimberley meetings (five meetings with between four and 30 attendees) including: **Elders** **Aboriginal health peak body representatives** **ACCHO representatives** **state and federal government health department representatives** **aged care and service provider representatives** **dementia peak body representatives** **dementia educators** **academics and consumer representatives** (See Appendix B for more detailed information about attendees). The aims of these events were:

- a) To share the findings and resources from the Let's CHAT Dementia research program with the wider community and actively facilitate translating and embedding them into practice;
- b) To facilitate partnerships between stakeholders working in this area;
- c) To identify priority areas for ongoing research in this area.

At each roundtable, attendees participated in semi-structured small-group discussions exploring these aims. Discussions were recorded in note form by designated scribes on each table. This report provides a summary of the combined feedback obtained during the three roundtable events. Relevant feedback obtained from the Kimberley meetings is also included to represent the remote context.

2. Stakeholder feedback

2.1 Awareness raising of resources and the best-practice model of care for cognitive impairment and dementia

Roundtable participants suggested a comprehensive range of strategies and avenues for: 1) promoting the study findings and resources; 2) helping to embed best-practice care for people with cognitive impairment and dementia in the primary health sector, and: 3) raising awareness within First Nations communities around Australia.

2.1.1 Professional sector

Suggested options for promoting and raising awareness about the Let's CHAT resources within the professional sector included online media: features in newsletters (e.g. WAPHA's Practice Connect, or RACGP's GP Connect); creating an online portal where resources can be accessed; integrating Let's CHAT resources into existing health information provision infrastructure (such as PHN Health Pathways websites), especially in providing best-practice dementia resources for GPs, and posting on the Australian Indigenous HealthInfoNet.

On the local health service level, key suggestions for improving health professional awareness and knowledge of dementia were through taking a holistic approach, avoiding silos and piggybacking onto other health programs, such as: longevity programs for Elders; incorporating discussions on brain health as part of domestic violence awareness-raising work; embedding best-practice dementia care knowledge in the Elder Care Support program nationally.

Finally, there was a strong appetite overall to build relationships across different sectors (ACCHOs, PHNs, Depts Health, mainstream primary care), and share knowledge and resources. This was particularly emphasised as important to avoid duplication. One suggested way to enhance relationships *between* sectors was through the creation of Communities of Practice (CoP) on Dementia Care in the form of yarning groups with health professionals working with Aboriginal and Torres Strait Islander peoples.

2.1.2 Community awareness sector

As well as promoting the resources to health professionals, there was a strong desire amongst roundtable attendees to actively focus on community awareness raising. Attendees believed it was important to educate Communities about the high rates of dementia and destigmatise the condition by helping people to recognise dementia as a disease, like any other. This includes education initiatives targeting younger people, who may not be at immediate risk of cognitive decline themselves, but could have family members with the disease. Providing them with knowledge about signs to look out for and how to get support if needed were seen as important. Attendees suggested: conducting dementia information sessions; generating community leadership in this space; and "building up local champions/Elders" – in paid roles – to "talk to Community about dementia and what they can do about it". Creating factsheets that could be shared with community was another suggestion.

Media sources such as NITV and other television channels, community radio (locally and nationally), or social media outreach programs were suggested as productive avenues for diffusion of brain health messaging. In the digital sphere, ACCHO Facebook pages, which are trusted and reliable sources of information for local community members, were suggested as good sites for diffusion of information to Community, and interfaces such as TikTok and Instagram were suggested to target younger people. Some attendees suggested large-scale campaigns involving high-profile people such as celebrities (e.g. football stars) to promote brain health and help to break down stigma around disclosing memory and thinking problems.

Within the health service context, ideas presented to help community awareness raising included: televising audiovisual resources (such as through the media platform Aboriginal Health TV or slideshows) and putting up posters. Both were suggested as ways to create good exposure to brain health promotion messaging in health service waiting areas and help lessen fear around getting cognitive checks.

Culturally grounded and culturally secure ways of engaging with Community described included: offering truth telling and sharing opportunities and making sure community members feel heard – talking to Elders about their life and their experience; discussing the impacts of colonisation, acknowledging past wrongdoings and working to break down institutionalised racism as a way to support wellbeing; storytelling or “sharing good stories”; emphasising the idea of “circularity” and the “cycle of life”; bringing in discussions of cultural healing; providing safe and culturally healing places; inviting community members to examine what spirituality means to them; emphasising strengths and; using language that community understands, in order “to reduce fear”.

2.2 Identified priority areas for further work

2.2.1 Health professional training and capacity building

Roundtable attendees spoke repeatedly about the importance of and need for health professional training in best-practice dementia care that is culturally specific to Aboriginal and Torres Strait Islander health service clients. It was also expressed that training needs to be ongoing, since the workforce is constantly in flux, and people who have received education in the past need to have repeated exposure to education, or ‘refreshers’. In the remote context, ongoing training was identified as crucial. In addition, it was highlighted that the remote nursing workforce, in particular, was characterised by frequent staff turnover and is therefore a key group requiring ongoing training.

Training in best-practice dementia care for all health professionals – e.g. GPs, nurses, allied health, mental health – was identified as important. The Aboriginal Health Worker/Practitioner (AHW/P) workforce was suggested as a key group for training across roundtable events and consultation in the Kimberley. Their integral role and connections within local communities puts them in an ideal position to identify and act upon any concerns regarding cognition or supports needed by clients. It was also repeatedly suggested that training (for all health professionals) should be formally recognised as a continuous professional development (CPD) activity.

Potential partnerships between researchers and Aboriginal Peak Health bodies present at the roundtables such as NACCHO and NATSIHWP were suggested to develop such training programs.

2.2.2 Changing the health and wellbeing landscape of Aboriginal and Torres Strait Islander people

Perhaps most importantly, roundtable attendees identified many entrenched issues that need to be addressed concurrently with advancing the research and practice agendas in order to achieve real change. There was an expressed need to build the Aboriginal health workforce. In particular, increasing the number of AHW/Ps in the primary care setting was seen as a top priority, as AHW/Ps are a “key link between community and services” and improve community members’ access to health care services.

On the flip side, several current challenges were highlighted that may impact initiatives to improve brain health outcomes for Community members. These include systemic staff shortages in primary care, problems with staff retention, and a lack of funding to improve this situation, coupled with examples of resistance from management due to the resourcing constraints. In the remote context, capacity constraints were perceived as compromising health professionals’ ability to enact best-practice dementia care; not enough time in a consult to do a health assessment, a need for “more people with skills around [best-practice dementia care]” and to be able to provide better continuity of care.

Roundtable participants expressed that future research should be Aboriginal/ACCHO-led, support self-determination and build ACCHOs' capacity to generate data and evaluate successful programs and include stories (showcase). Building the local Aboriginal research workforce and Aboriginal leadership of research was also a clear priority in the Kimberley. There was a desire to address systemic flow issues – e.g. a dedicated project aiming to support health services to make software changes to improve systems (ie. embed recalls for cognitive screening, make changes to Aboriginal Health Check templates). A project to test the efficacy of embedding the best-practice model of care into ACCHOs nationally was also proposed. Monitoring the use of and level of satisfaction with the resources developed as part of the Let's CHAT program was also suggested as an important research activity.

2.2.3 Focusing on dementia prevention

The importance of initiatives for dementia prevention were discussed. Taking a life-course approach in addressing brain health was highlighted: targeting younger community members – e.g. working with schools and sporting communities to educate young people about the importance of avoiding head injury; or raising community awareness about what we can do to enhance our brain health (decrease or eliminate modifiable dementia risk factors and increase protective factors). The connection between mental health concerns – psychological trauma, depression, and social isolation – and dementia was also discussed, including the need to track and address these concerns better, with counselling initiatives, for example. In particular, the traumatic impacts on the Stolen Generation and their families were highlighted. The role that addiction plays in contributing to risk factors (such as smoking to deal with trauma) was also recognised.

2.2.4 Expansion of scope to mainstream acute, primary and aged care services

Several attendees drew attention to the fact that there are Aboriginal and Torres Strait Islander peoples not attending ACCHOs. This group, and the health professionals caring for them, need to be brought into future research and dementia education initiatives, as the work to date has focussed on the ACCHO context. Raising awareness and (if necessary) tailoring of the current resources was suggested as a way to maximise the impact in mainstream primary and aged care services.

It was noted that more understanding was needed around use of mainstream services, in terms of equity of access, both geographically and culturally. Improving cultural security for Aboriginal and Torres Strait Islander people attending health care services, in particular mainstream primary care and aged care services, was also discussed. Health care workers need to have cultural safety and trauma-informed training. In the remote setting, the need to provide best-practice dementia care training to health professionals working in acute care was emphasised.

Expanding culturally specific education and resource provision into community and residential aged care was also highlighted as an area for development. As was developing ACCHOs' capacity as aged care providers.

2.2.5 Looking after the carers

Carers of people living with dementia were described as the 'unsung heroes' in the landscape of dementia care. Roundtable attendees pointed out that the partners, family members and/or friends of the person living with dementia in an informal carer role should be the focus of future work as they often need more support. Carers commonly suffer from burnout, have their own health issues to contend with (including cognitive issues potentially), and may also be caring for other family members, such as children or grandchildren. Carers need support during the time they are caring for people with dementia, and also after the person passes.

One suggestion for outreach was to establish yarning groups for carers where they could share and debrief with other carers who understood what they were experiencing. Counselling support was also recommended. Further research was needed into the experiences, health and support needs of informal carers.

It was also acknowledged, however, that making contact with carers and getting resources to them could be difficult at times, and that respite services can be inaccessible to carers due to cost. In the Kimberley, it was emphasised that the current funding model does not support the remote context or meet the needs of remote-living carers.

2.2.6 Policy

Policy aspects discussed by the roundtable participants included:

- Engaging with decision makers to show them our work (the roundtable being an example of doing this, but others could be guest presenting at Dept Health meetings, including state governments as they are funded for dementia initiatives);
- Prioritising rapid translation of research outcomes;
- Working with PHNs to raise awareness and help disseminate resources;
- The need to adequately address the needs of Aboriginal and Torres Strait Islander Communities in the National Dementia Action Plan;
- Explore collaboration with NACCHO to further develop and disseminate best-practice model of care;
- Ensure that any mainstream stakeholders involved understand that this agenda has to be informed and preferably led by Aboriginal and Torres Strait Islander people;
- It is essential to consult with Community about what they want – asking ‘What’s important to you regarding dementia?’;
- Funding considerations:
 - Re-imagining how dementia care is funded at the federal level, with a suggestion that more structure is needed in the referral pathways;
 - Recognising that ongoing and repeat training is expensive, but essential;
 - Factoring the sustainability of initiatives into planning – programs need to be ongoing, continuity of funding needs to be improved.

3. Discussion and conclusions

This report has summarised the feedback obtained from the roundtable events held as part of the Let’s CHAT Dementia dissemination strategy and consultation within the Kimberley from a remote area perspective. It details suggestions regarding how best to raise awareness of the best-practice model of care and resources developed in the Let’s CHAT Dementia project. Further, it identifies potential partnerships and priority areas for ongoing research and other work that will support positive outcomes for Aboriginal and Torres Strait Islander people at risk of or living with cognitive impairment or dementia, and their carers, families and Communities.

The process of consultation was found to be successful, with a positive response and good representation from each of the stakeholder groups at the three roundtable events. Attendees valued the opportunity to meet and network with stakeholders in Aboriginal health, dementia research and aged care from different organisations and community groups. It was also reassuring that the suggestions made during roundtable sessions are congruent with the approaches taken during the Let’s CHAT Dementia project. This reinforces the strength and importance of the project being co-designed with our ACCHO partners who were clearly very skilled at identifying effective ways to engage with Community.

Equipped with the feedback outlined in this report, provided by the stakeholders who generously devoted their time to attend the Let's CHAT Dissemination Roundtables and share their ideas and brainstorm together, we have established some priorities for next steps:

- *Sharing the Let's CHAT model of care work and resources as widely as possible.* An extremely positive byproduct of the roundtable events was the many, many connections we formed with the wide range of stakeholders who participated. As a result, the Let's CHAT team has been invited to present at several government special interest groups, communities of practice, and other meetings over the past year. We will continue to seek and take advantage of opportunities to disseminate this work and explore potential partnerships for ongoing work in this space.
- *We have developed a research agenda* that combines the findings from our previous research with the roundtable feedback, and includes the following components:
 - A key focus on ensuring research initiatives are Indigenous-led, build the Aboriginal and Torres Strait Islander research workforce and involve Community at all stages;
 - A community awareness raising program, including the development and evaluation of media and social media campaigns, and initiatives to create locally based dementia champions;
 - Developing Dementia Care CoPs;
 - Incorporating brain health into other existing health promotion and wellbeing campaigns;
 - Developing a training unit for AHW/Ps to be incorporated into accredited TAFE training programs, as well as best-practice dementia care training to upskill trained health workers, with accredited CPD points;
 - Projects focussing on carers, notably to identify how best to reach them in the first instance, and also how they can be best supported.

Some of these research ideas are already being progressed, and the roundtables were timely in providing essential community and stakeholder feedback to confirm the relevance and importance of these initiatives. For suggested ideas or programs that are not yet underway, there are now clear directions for future projects and work-focus areas.

- Take opportunities to draw attention to the fact that successful dementia training and research outcomes are contingent on adequate and continuous funding. Many of the activities and strategies adopted through the Let's CHAT Dementia program and suggested through the roundtables as future strategies are resource intensive. Continued and specific funding are needed to preference the implementation of strategies that have been shown to be effective.

Finally, alongside our research findings, the valuable feedback obtained from the roundtable events will also be used to inform a policy document we are co-developing on optimising brain health for Aboriginal and Torres Strait Islander peoples. All of this work happens in the wider context of the lived experiences of Aboriginal and Torres Strait Islander peoples. The group was clearly reminded by one of the Community Elders at the Melbourne Roundtable to never forget the importance of acknowledging and addressing the ongoing impacts of colonisation when working to promote brain health and wellbeing.

Appendix A. About the Let's CHAT Dementia project

A.1 Study design

The Let's CHAT Dementia Project was a stepped-wedge cluster randomised controlled trial, enabling all ACCHSs to participate in the implementation. The implementation aims were:

- Completion of six education workshops for ACCHS staff and two GP workshops;
- Practice change initiatives customised to each setting (e.g. changes to the Older Person's Aboriginal Health Check to include cognitive section);
- Recruitment of a dementia champion at each ACCHS.

Six-monthly audits tracked progress on cognitive measures throughout the study. Audits also tracked clients for whom the health service had identified concerns around cognition, who were invited to participate in a comprehensive geriatric assessment, with recommendations for any follow-up care fed back to participants and their health service.

A.2 Let's CHAT Dementia Results Summary

What the numbers show

The two co-primary outcome measures were: 1. Detection of cognitive impairment or dementia; 2. Evidence of concerns being raised around cognition, plus uptake of the diagnostic pathway - measured as documentation of two or more of: cognitive assessment, dementia blood screen, neuroimaging (CT- or MRI-brain) or referral to specialist services. Key study results are summarised below. Charts 1 and 2 show rates of cognitive impairment and concerns raised during each audit period, respectively. Chart 3 shows the significant change in rates of pathway uptake, which almost tripled across the study timeline from 3.3% to 9.2%.

Chart 1: Number and percentage of clients with cognitive concerns

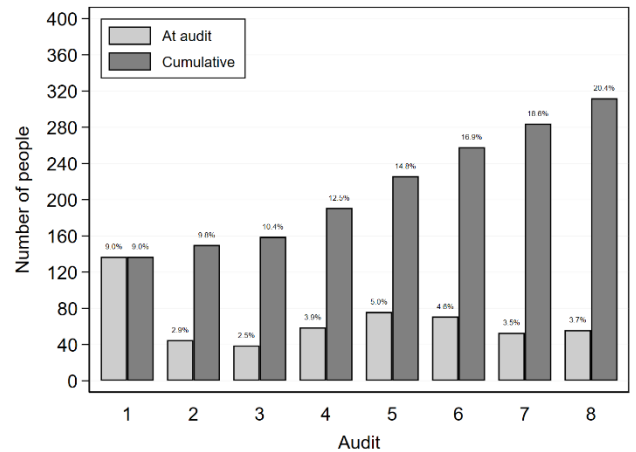


Chart 2: Rates of cognitive impairment identified (number and %)

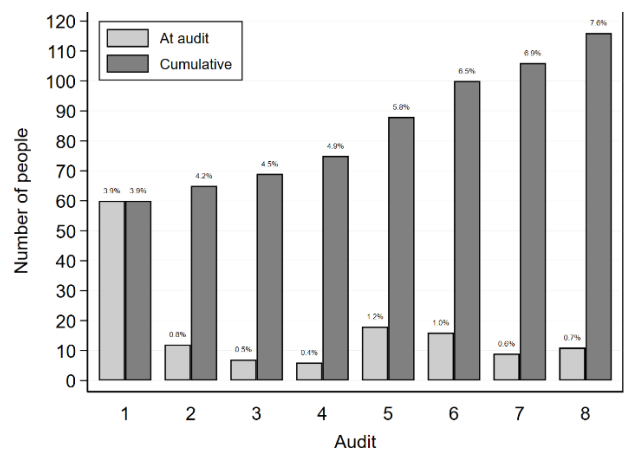
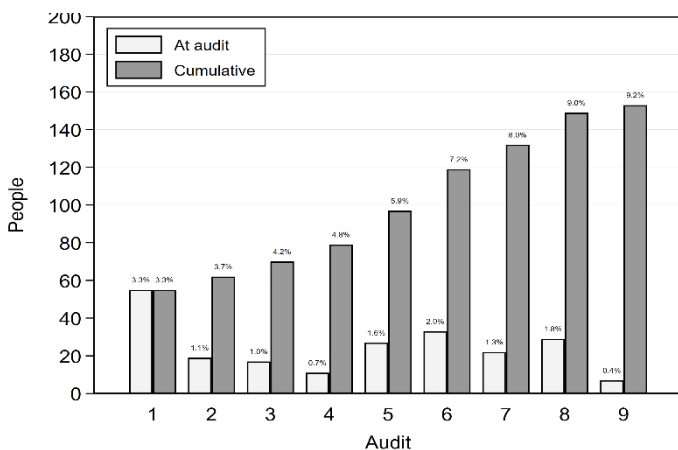


Chart 3: Rate of uptake of the dementia detection and management pathway (number and %)



n=1530
Mean age
60.3±8.2 years

These findings indicate that the Let's CHAT Project led to improvement in uptake of the dementia detection & management pathway.

A.3 Resources

A range of initiatives and resources were developed and trialled during the study, including:

1. A Best-practice guide to cognitive impairment and dementia care for Aboriginal and Torres Strait Islander people attending primary care
2. A [Webinar series](#) on best-practice care for cognitive impairment and dementia
3. Educational videos for health professional staff on [how to do a KICA cognitive assessment and how to talk about memory and thinking problems](#) with patients
4. Community awareness-raising [advertisements](#)
5. Software adaptations to include updated Older Persons' Aboriginal Health Check (MBS 715) templates, which incorporate questions about cognition and a lower age threshold (in 50% of partner ACCHSs).
6. [GP Management Plan recommendations](#) for people at risk of cognitive impairment, people living with cognitive impairment/dementia and carers of people living with cognitive impairment/dementia.



3.4 Study initiatives:

7. Training for ACCHS staff on how to conduct cognitive assessments
8. Engagement of health professionals during the workshops with over 620 attendees.
9. Collaborative community outreach programs.
10. Feedback of findings to each of the ACCHS partners.

All of this was undertaken in the midst of considerable disruptions due to the COVID pandemic, high turnover of staff and difficulty recruiting and retaining dementia champions.

Appendix B. Attendees at Let's CHAT Roundtables and ACCHS feedback sessions

Table 1. Number of attendees at each Let's CHAT Roundtable by organisation/affiliation

Organisation /Affiliation	Sydney	Perth	Melbourne	Total
Researcher	7	7	12	26
Study ACCHS partner	2	1	5	8
State Govt	1	2	2	5
Federal Govt		2	3	5
Local ACCHO/Aboriginal Aged Care		4	7	11
Local mainstream primary/aged care/PHNs		1	3	4
Aboriginal Health Peak Body	1	3	3	7
Dementia Peak Body	3	2	2	7
Local Elder/ Elder Representative Body	2	1	2	5
Carer			1	1
Total	16	23	40	79

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