Developing mild cognitive impairment and dementia data in Aboriginal and Torres Strait Islander-specific primary healthcare services

A collaborative project facilitated by the OnTRACK Centre of Research Excellence

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We acknowledge the Traditional Owners of all the unceded lands across Australia and are grateful to the Traditional Owners, Elders and Knowledge Holders of all Aboriginal and Torres Strait Islander nations and clans.

We recognise the unique place held by Aboriginal and Torres Strait Islander peoples as the original owners and custodians of the lands and waterways across the Australian continent, with histories of continuous connection dating back more than 60,000 years. We also acknowledge the enduring cultural practices of caring for Country.

We pay respect to Elders past, present and future, and acknowledge the importance of Aboriginal and Torres Strait Islander peoples' knowledge in the Academy. As a community of researchers, clinicians, policy makers, and advocates we are privileged to work, research and learn together as we collaborate to address inequity and build better health and wellbeing with Aboriginal and Torres Strait peoples and Communities.

We also acknowledge members of the Stolen Generations and their families.

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EXECUTIVE SUMMARY

Aboriginal and Torres Strait Islander peoples hold rich knowledges, cultural practices and Community and kinship connections that can contribute to protecting brain health across the life course. Although these strengths are enduring, the cumulative effects of colonisation, socioeconomic disadvantage, educational inequity, and high rates of modifiable risk factors and chronic health conditions experienced by Aboriginal and Torres Strait Islander peoples, impact brain health. Accordingly, mild cognitive impairment (MCI, also known as mild neurocognitive disorder) and dementia disproportionately affect Aboriginal and Torres Strait Islander peoples. Population ageing and changing social, environmental and commercial determinants of health are anticipated to lead to a greater future burden of MCI and dementia.

High-quality and comprehensive MCI and dementia data are needed to understand and monitor dementia rates and to inform evidence-based policy, service provision and planning. Yet MCI and dementia data gaps among priority populations, such as Aboriginal and Torres Strait Islander peoples, are consistently recognised across national dementia policy frameworks. This includes the National Dementia Data Improvement Plan 2023–2034 and the National Dementia Action Plan 2024-2034. As a key provider of healthcare for Aboriginal and Torres Strait Islander peoples, Aboriginal and Torres Strait Islander-specific primary healthcare services (APHSs) play a critical role in recognising when people have the signs and symptoms of cognitive impairment. These services are essential to timely detection and diagnosis for people living with MCI and dementia, and for data collection. There is currently no systematic or centralised data collection of Aboriginal and Torres Strait Islander peoples living with MCI or dementia who access APHSs. The current lack of data available on Aboriginal and Torres Strait Islander peoples accessing APHSs limits our understanding of the impact of dementia on health outcomes and patterns of service use, particularly in remote areas where these may be the only accessible services for the local population.

As a critical first step in addressing MCI and dementia data gaps among Aboriginal and Torres Strait Islander peoples, the Australian Institute of Health and Welfare (AIHW) National Centre for Monitoring Dementia (NCMD) commissioned the University of Melbourne to lead a project to identify opportunities and strategies to improve the collection, availability and quality of data relating to Aboriginal and Torres Strait Islander peoples living with MCI or dementia who attend APHSs.

The specific objectives for this project were to:

1. Identify the current MCI and dementia data environments within APHSs i.e. current data holdings, collection methods, data users and data use;
2. Identify data needs from Aboriginal and Torres Strait Islander communities and service providers in relation to MCI and dementia and;
3. Develop and provide a rationale for recommendations to improve the availability and quality of MCI and dementia data among Aboriginal and Torres Strait Islander peoples from APHSs, including enablers for systematic collection.

This three-phase project was guided by an Aboriginal and Torres Strait Islander Data Governance Group and included:

- Phase 1: A desktop review to identify existing Aboriginal and Torres Strait Islander MCI and dementia data collections.
- Phase 2a: A qualitative key informant study involving 28 APHS healthcare providers and dementia data interest holders.
- Phase 2b: A national cross-sectional survey of APHS representatives.
- Phase 3: Development and refinement of recommendations with input from a national panel of experts.

The desktop review found no dementia data collections based on direct reports from APHSs and that current prevalence estimates rely on a small number of cross-sectional studies in selected Australian jurisdictions and national projection estimates. Key informant interview-yarns and survey results highlighted multidimensional, interrelated factors influencing poor data quality. These included health system-related issues, such as limited access to specialist cognition services, non-standardised assessment and documentation processes, limitations in clinical information systems (CISs), variable workforce capabilities, and competing priorities in the primary healthcare environment. There were also clinical care challenges such as underdiagnosis of MCI and dementia, clinical complexity, clinical inertia and dementia-related stigma. APHS interest holders emphasised the need for robust data governance frameworks that uphold data sovereignty principles, reciprocal data-sharing arrangements between APHSs and external organisations (including the AIHW), and sustained dementia and data literacy training for APHS staff to support future dementia data development initiatives.

Project findings informed the development of draft recommendations that were reviewed and refined by a national panel of experts. The final 17 recommendations, each with an accompanying rationale, provide advice for the AIHW, other government agencies, and the wider Aboriginal and Torres Strait Islander health sector on key actions needed to improve the availability and quality of MCI and dementia data in APHSs (Executive Summary Table). They cover health system, health service, healthcare provider and Community-individual level recommendations, and are underpinned by three guiding principles: (i) upholding Aboriginal and Torres Strait Islander data governance and data sovereignty, (ii) co-design and collaboration and (iii) strengths-based approaches.

Recommendations to strengthen the availability and quality of MCI and dementia data in Aboriginal and Torres Strait Islander-specific primary healthcare services

No.	Health system recommendations	Timeframe for implementation*
1	Explore opportunities to strengthen existing, and establish new, Aboriginal and Torres Strait Islander health-specific data governance roles that include oversight of primary healthcare data.	Medium
2	Develop nationally agreed standards and a guide for two-way data sharing for dementia related data, that can be adapted to local service needs and preferences.	Medium
3	Ensure all APHSs have access to culturally safe and trauma-informed specialist cognition services to support diagnosis and care of Aboriginal and Torres Strait Islander peoples at risk of or living with dementia.	Long
4	Develop a measure in the OSR to report on and monitor access to specialist cognition services.	Short
5	Consider adding a cognition or dementia-related service indicator to primary healthcare performance reports; nKPI for Aboriginal and Torres Strait Islander primary healthcare sector and PIPQI measures for mainstream primary healthcare services.	Medium
6	Promote the AIHW Dementia National Best Practice Data Set in national conversations about standardisation of CISs data collection and develop an implementation guide for primary care providers.	Medium
7	Support workforce capacity in the Aboriginal and Torres Strait Islander-specific primary healthcare sector to address clinical and data needs and preferences.	Ongoing
8	Conduct a feasibility study to develop a method that can better estimate Aboriginal and Torres Strait Islander population prevalence of MCI and dementia.	Medium
9	Strengthen the identification of Aboriginal and Torres Strait Islander peoples in existing administrative collections (e.g. primary healthcare, hospital data, aged care).	Medium
10	Improve intra- and inter-operability of CISs (within the Aboriginal and Torres Strait Islander-specific primary healthcare sector and between primary healthcare and secondary/tertiary care).	Medium
11	Ensure ongoing advocacy for dementia as a health priority.	Ongoing

No.	Health service recommendations	Timeframe
12	Implement strategies to increase standardisation of dementia documentation in CISs e.g. use of standardised clinical items in health records (atomic/discoverable data).	Medium
13	Include memory and thinking questions in annual health check templates for people over 50 years.	Medium
No.	**Healthcare provider recommendations**	**Timeframe**
14	Support availability of ongoing training for healthcare providers working in APHSs to provide ***culturally safe and trauma-informed care.***	Ongoing
15	Support availability of ongoing ***dementia training*** for healthcare providers working in APHSs to build capacity and confidence to recognise signs and symptoms of cognitive impairment, to conduct case finding and culturally safe dementia assessments, and to follow optimal dementia care clinical guidelines.	Ongoing
16	Support availability of ongoing training for healthcare providers working in APHSs to build knowledge and skills about ***health record keeping and data literacy***, and to strengthen capabilities of services to use data internally.	Ongoing
No.	**Community-Individual recommendation**	**Timeframe**
17	Identify opportunities for health promotion and Community education about dementia, based on a life course approach.	Medium

APHSs, Aboriginal and Torres Strait Islander-specific primary healthcare services; CISs, clinical information systems; nKPI, national Key Performance Indicator; OSR, Online Services Report; PIPQI, Practice Incentive Program Quality Improvement; MCI, mild cognitive impairment

*Suggested implementation timeframe based on impression of feasibility, system readiness and complexity of action. Development of a formal implementation plan is required. Short term, within 1 year; medium term, 1 to 3 years; long term, 3 years and longer. Many of the recommendations require initial and ongoing implementation; in this case, the ongoing timeframe is not included. Some are only meaningful as having an ongoing timeframe for implementation.

This project has taken a robust and collaborative approach to identifying opportunities and strategies that will improve the collection, availability and quality of data relating to Aboriginal and Torres Strait Islander peoples living with MCI or dementia who attend APHSs. The recommendations, developed with significant input from the field, offer comprehensive and practical guidance on the way forward, with the ultimate aim of delivering better, data informed care to Aboriginal and Torres Strait Islander peoples living with MCI or dementia.

1. BACKGROUND

1.1 Mild cognitive impairment and dementia among Aboriginal and Torres Strait Islander peoples

Mild cognitive impairment (MCI) is a brain condition that involves subtle changes to memory and thinking that are generally not severe enough to interfere with independent living, are not a normal part of ageing, and may increase an individual's risk of developing dementia.[1] Dementia describes a collection of conditions characterised by cognitive impairment and changes in brain function that impact people's memory, thinking and ability to perform activities of daily living.[2] Dementia has far-reaching consequences for the diagnosed person, their family and friends, the wider community, the service system and the economy.[3] The number of people living with dementia and disability, the burden on carers and dementia-related healthcare costs are projected to grow exponentially over the next 30 years.[4] The Aboriginal and Torres Strait Islander population is projected to grow substantially in the coming decades, increasing from 798,000 in 2016 to 1.89 million by 2051, with the proportion of Aboriginal and Torres Strait Islander peoples aged 45 years and older projected to increase from 20.9% in 2016 to 27.1% by 2051. By mid-century, the number of Aboriginal and Torres Strait Islander peoples aged 50 years and older living with dementia is likely to be 5.5 times the 2016 estimate.

Aboriginal and Torres Strait Islander peoples hold rich knowledges, cultural practices and Community and kinship connections that can contribute to protecting brain health across the life course.[7, 8] Despite these enduring strengths, the cumulative effects of colonisation, educational inequity, socioeconomic disadvantage and the high rates of modifiable dementia risk factors and chronic health conditions experienced by Aboriginal and Torres Strait Islander peoples impact brain health. Consequently, dementia disproportionately affects Aboriginal and Torres Strait Islander peoples, often presenting with onset at a younger age[9] and prevalence up to five times that documented among non-Indigenous Australians.[10, 11] Furthermore, MCI and dementia are widely under-recognised in healthcare settings, including primary healthcare, despite the importance of timely detection and diagnosis for responsive and effective care.[3] As such, improving detection and management of dementia is a Community priority identified in the national *Aboriginal and Torres Strait Islander Dementia Research and Translation Roadmap* developed with 342 Community interest holders.[12]

1.2 Detection, diagnosis and documentation of MCI and dementia in the primary healthcare setting

Services that deliver primary healthcare to Aboriginal and Torres Strait Islander peoples in Australia are heterogeneous, with great variety in funding structures, geographical settings, size and governance structures. They include private practices, not-for-profit community organisations and Aboriginal and Torres Strait Islander-specific primary healthcare services (APHSs). APHSs were established to provide culturally responsive, comprehensive, high-quality primary healthcare throughout the life course that acknowledges the impact of social, cultural and historical determinants of health that are essential to improving health outcomes.[13, 14] There are two main types of APHSs: Aboriginal Community Controlled Health Organisations (ACCHOs) and non-ACCHO APHSs. The majority of ACCHOs and non-ACCHO APHSs receive funding from the Australian Government through the Indigenous Australians' Health Programme (IAHP).[13] ACCHOs are Community-run primary healthcare services that provide comprehensive and culturally safe care to Aboriginal and Torres Strait Islander clients. Approximately half of the Aboriginal and Torres Strait Islander population nationally attend ACCHOs,[15] valuing them as accessible, welcoming and culturally safe spaces.[16] Non-ACCHO APHSs are a mix of government-run organisations (such as local health districts) and non-government organisations (such as private or not-for-profit healthcare services). As a key provider of healthcare for Aboriginal and Torres Strait Islander peoples, APHSs play a critical role in recognising symptoms of cognitive impairment, timely detection and diagnosis of dementia and the provision of post-diagnostic care, including referrals to specialists and support services.

Best-practice guidance on MCI and dementia care for Aboriginal and Torres Strait Islander peoples attending primary healthcare recommends clinical assessment for MCI and dementia in response to: (i) identifying those at high risk and (ii) symptoms or concerns being raised around cognition by the client themselves, a family member, or by a healthcare provider (e.g. through observation of behaviour or directly asking questions about memory and thinking).[17] Engagement in healthcare and documenting a person's clinical information in individual health records are the first steps in the primary healthcare data journey (Figure 1).[18] Therefore, identifying and documenting a person's clinical details, including symptoms and diagnoses, is the foundation on which high-quality primary healthcare data is built.[19] Optimal care for patients requires accurate, high-quality dementia data. This also enables effective management of government resources, healthcare planning and delivery.

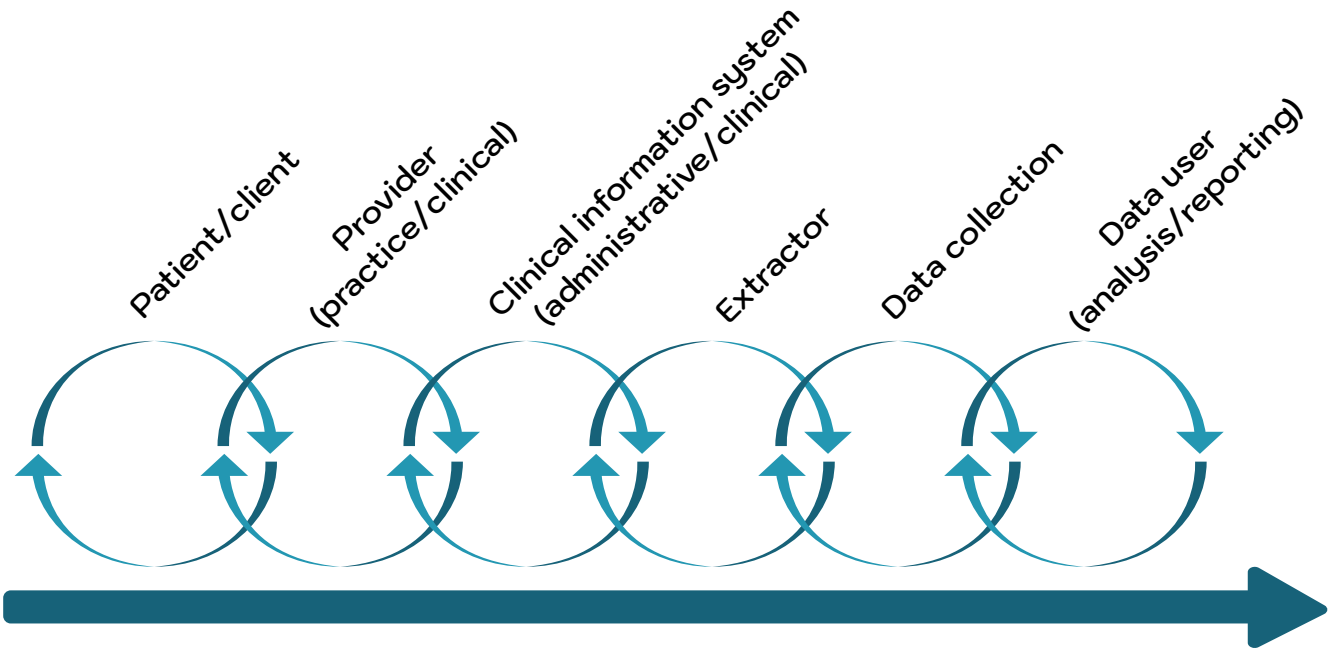


Figure 1. *The primary healthcare data journey is the transfer of clinical patient information (e.g. dementia diagnosis), collected by healthcare providers from patients, to a national collection. It involves several points of interpretation and transformation as data are transferred from one system to another*[18]

1.3 Developing dementia data: a national priority

Developing dementia data is a national priority and high-quality, comprehensive dementia data are needed to document and monitor dementia and to inform evidence-based policy, service provision and planning. Yet, dementia data gaps are consistently recognised across national dementia policy frameworks. The aim of the *National Dementia Data Improvement Plan 2023–2034* (NDDIP) is to strengthen national dementia data for population-level monitoring, research, and reporting in order to improve outcomes for all people living with dementia, and their carers, families and communities.[20] Among the 14 dementia data gaps identified, the NDDIP highlights the need for improved data among priority populations, including Aboriginal and Torres Strait Islander peoples. Although a range of data is collected through national reporting by APHSs, including through the Online Services Report (OSR) and the national Key Performance Indicators (nKPI) collection, neither of these reports include cognition or dementia-related indicators (see Box 1).

Box 1: Online Services Report (OSR) and the national Key Performance Indicators (nKPI)

The OSR is reported by organisations receiving funding under the IAHP and contains contextual information about each organisation as well as aggregate counts of number of clients, episodes of care and full time equivalent staffing levels.

The nKPIs are reported by organisations receiving funding under the IAHP with the purpose of supporting continuous quality improvement (CQI) activity among service providers. The nKPIs are primary healthcare indicators that focus on maternal and child health, preventive health and chronic disease management to evaluate progress towards achieving the goals of the National Aboriginal and Torres Strait Islander Health Plan and Closing the Gap health outcomes.

In addition, there is currently no systematic or centralised data collection on Aboriginal and Torres Strait Islander peoples living with MCI or dementia who access APHSs.[20] The current lack of available data on Aboriginal and Torres Strait Islander peoples accessing APHSs limits our understanding of the impact of dementia, health outcomes and patterns of service use, particularly in remote areas where APHSs may be the only accessible services for the local population.

The NDDIP also guides activities required to assess the performance of the *National Dementia Action Plan 2024–2034* (NDAP). The NDAP states that improved dementia data is required to maximise the impact of dementia research, promote innovation, increase dementia awareness, reduce the population's risk of dementia and improve service coordination for those affected. Improved dementia data is one of the three priority actions in the *Collective Priority Framework for 2025-2027*. Alongside dementia-specific policy frameworks, guidance on data governance practices is available. The Australian Government Department of Health, Disability and Ageing (DHDA) *Governance of Indigenous Data Implementation Plan* provides clear strategies, based on principles of partnership with Aboriginal and Torres Strait Islander peoples, for ownership and control of Indigenous data.[21, 22] *The National Agreement on Closing the Gap* Priority Reform Four emphasises the importance of shared access to data and the need to increase the number of regional data projects that support Aboriginal and Torres Strait Islander communities to make decisions about Closing the Gap and their development.[23] There is an urgent need to address dementia data gaps for Aboriginal and Torres Strait Islander peoples. This will better guide prevention initiatives, service planning and delivery, and better support the wellbeing of people living with MCI or dementia, and their carers, families and communities.

2. PROJECT BACKGROUND, AIMS AND OBJECTIVES

2.1 Project background

In 2021, the DHDA contracted the Australian Institute of Health and Welfare (AIHW) to establish a new National Centre for Monitoring Dementia (NCMD). This includes funding to enable the AIHW to work with external organisations to address priorities for data development and improvement through Dementia Data Partnership Projects. As a critical first step in addressing dementia data gaps among Aboriginal and Torres Strait Islander peoples, the AIHW NCMD commissioned the University of Melbourne to lead an Aboriginal and Torres Strait Islander Dementia Data Development consultancy project (this project).

2.2 Aims and objectives

The overarching aim of this project was to engage with Aboriginal and Torres Strait Islander health and dementia data interest holders, including primary healthcare service providers and relevant experts in population health research, to: i) understand whether data on MCI and dementia are collected by APHSs, and if collected, how they may be improved and used for dementia monitoring among Aboriginal and Torres Strait Islander people or; ii) if not collected, provide advice on opportunities and strategies for data collection to enable monitoring of MCI and dementia.

The stated objectives for this project were to:

1. Identify the current MCI and dementia data environments within APHSs i.e. current data holdings, collection methods, data users and data use.
2. Identify data needs from Aboriginal and Torres Strait Islander communities and service providers in relation to MCI and dementia.
3. Develop and provide a rationale for recommendations for improving the availability and quality of MCI and dementia data among Aboriginal and Torres Strait Islander peoples from APHSs, including enablers to systematic collection.

3. PROJECT PROCESSES

3.1 Ethics approval

Ethical approval for this project was obtained from the University of Melbourne Human Research Ethics Committee (Project ID 32352), the Aboriginal Health and Medical Research Council Ethics Committee (2437/25), the Western Australian Aboriginal Health Ethics Committee (HREC1433) and the Australian Institute of Aboriginal and Torres Strait Islander Studies Ethics Committee (REC-0584).

3.2 Project team and governance

Led by The University of Melbourne in collaboration with our academic partners (University of Western Australia, University of Notre Dame, James Cook University), this project was governed by an Aboriginal and Torres Strait Islander Data Governance Group (DGG) and supported by a Research Working Group (RWG). The role of the DGG (Chaired by Prof Sean Taylor – Dauareb, Mer Island, Eastern Torres Strait) was to provide cultural oversight and input with a focus on Indigenous data governance and data sovereignty principles. Additional clinical, content, methodological, technical and policy expertise in relation to dementia, Aboriginal-specific primary healthcare and large data collections and management was provided by the RWG. (Figure 2).

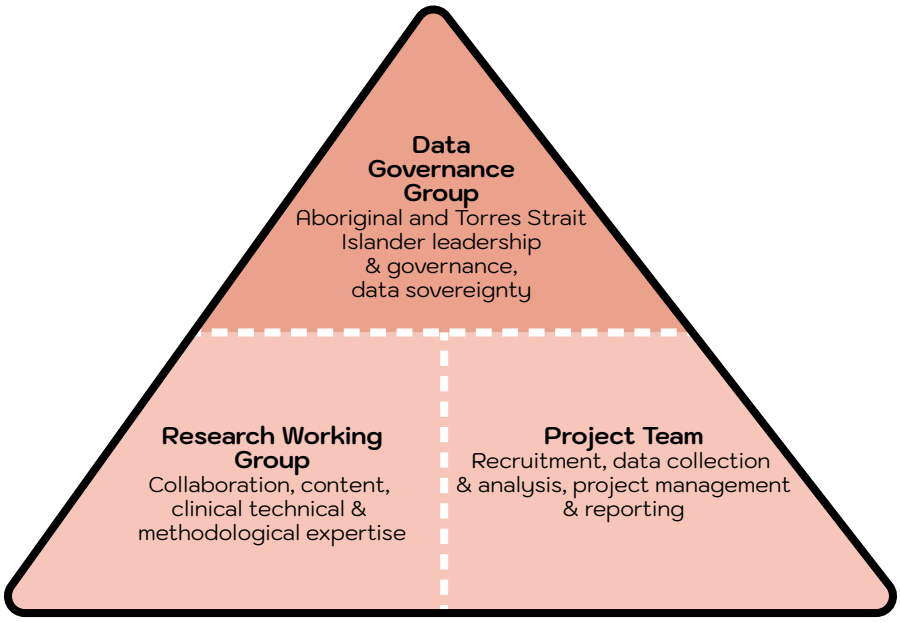


Figure 2. *Project governance structure*

3.3 Project overview

To address the AIHW's stated objectives, we designed a three-phase exploratory, sequential mixed-methods study[24] (Figure 3) guided by overarching principles of collaboration and cultural security.[25] Cultural security is a methodological and ethical consideration that emphasises that Aboriginal and Torres Strait Islander health research must be conducted in a manner that prioritises Aboriginal and Torres Strait Islander cultural values, beliefs and ways of knowing and doing without compromising the cultural rights, expectations, needs and preferences of Aboriginal and Torres Strait Islander peoples.

The three phases of the project (Figure 3) included:

- Phase 1: A desktop review to identify existing relevant data collections.
- Phase 2a: A qualitative key informant study using interviews and research yarning[26] to explore current data collection processes and future needs in APHSs.
- Phase 2b: A national cross-sectional survey distributed to APHSs.
- Phase 3: An expert panel workshop to refine project recommendations.

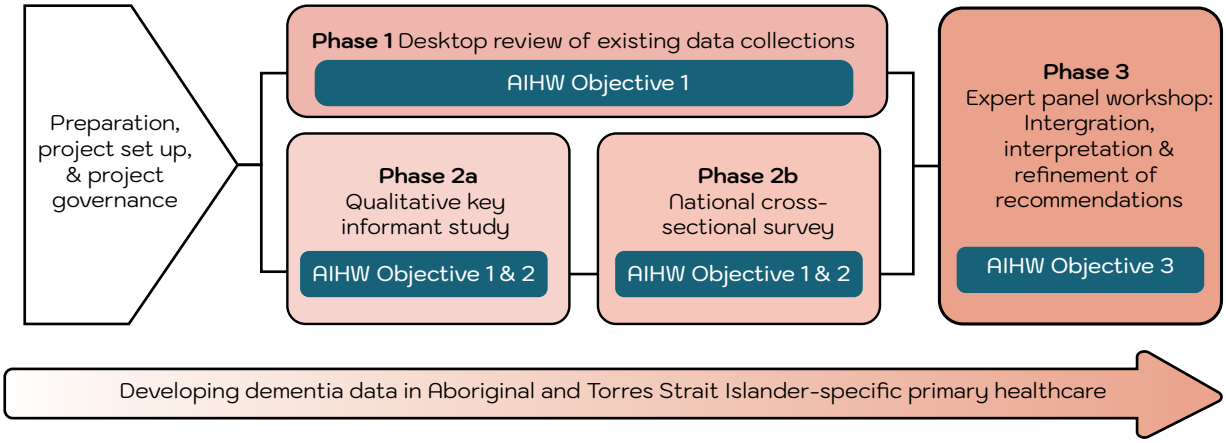


Figure 3: *Overarching mixed-methods study design*

3.4. Scope and setting

In consultation with the AIHW NCMD, we expanded the scope of the project to include both ACCHOs and non-ACCHO APHSs nationally as they share the same commitment to providing holistic, comprehensive and culturally safe healthcare to Aboriginal and Torres Strait Islander peoples. It is important to note that approximately half of Aboriginal and Torres Strait Islander peoples attend mainstream primary healthcare services, but these were not included in this project and we did not seek to compare or contrast issues experienced by APHSs with those experienced by mainstream primary healthcare services. Whilst this project contributes, in part, to the overarching aim of population-level dementia data monitoring, there are existing and ongoing national data development initiatives that aim to improve mainstream primary healthcare data. This project should be considered in this context; for example, AIHW's work developing a National Primary Health Care Data Collection (NPHCDC). Although we acknowledge the importance of monitoring dementia risk and protective factors in order to understand a population's risk profile and how this impacts the rate of dementia and trends over time,[20] including data on risk factors was not within the scope of this project.

Box 2: A note on terminology

For the purposes of this project, we defined data documentation/collection and data use as follows:

Data documentation/collection: Health record keeping i.e. recording of individual health data or clinical information within consultations e.g. recording a dementia diagnosis in a clinical information system (CIS).

Data use:

Internal (to health service): data collection and coding, monitoring or quality improvement (QI), program development and service delivery, reporting to Community, research.

External (to health service): monitoring, reporting to external organisations (e.g. AIHW), funding, research.

3.5 Phase 1: Desktop review

Objectives

- To identify the current MCI or dementia data environments within APHSs i.e. administrative datasets, current data holdings, or datasets with the potential to include MCI or dementia data for Aboriginal and Torres Strait Islander peoples.
- To explore and describe each dataset identified, including information on:
    - The data holders and owners of each dataset.
    - How the data was collected and coded.
    - Who currently accesses and/or uses each dataset.
    - Any limitations (legal or cultural) placed on the use of the data.

Desktop review process

We performed a desktop review using a modified, grey literature[27] search and scientific database search to identify data collections that included: i) MCI and dementia diagnoses, ii) Aboriginal and/or Torres Strait Islander status, and iii) access to or utilisation of APHSs. Grey literature is defined as information or evidence that is produced on all levels of government, academia, business and industry, but which is not controlled by commercial publishers.[27] Common grey literature resources include government reports, policy documents, technical reports, practice guidelines and conference proceedings. Searches involved advanced Google searches, searches of relevant government websites (e.g. AIHW, Australian Bureau of Statistics [ABS]) and a search of academic databases (Scopus, Web of Science, Australian Indigenous HealthInfoNet). We screened search results to identify in-scope data collections and for resources that met our inclusion criteria. Full-text resources were read to identify: i) the primary source of data i.e. whether the study was reporting new data, and ii) how the data were collected, or iii) whether the study was using secondary or previously reported data. Citation searching (i.e. searching reference lists of relevant materials) and consultation with subject-matter experts (including DGG, RWG and AIHW representatives) were used to identify any additional relevant data collections.

3.6 Phase 2a: Qualitative interviews with APHS providers and interest holders

Objectives

- To explore current data collection practices i.e. recording clinical information among APHS healthcare providers in relation to MCI and dementia.
- To explore barriers and enablers to MCI and dementia data collection and use among APHS healthcare providers.
- To explore APHS healthcare providers' data needs and preferences in relation to Aboriginal and Torres Strait Islander peoples with MCI and dementia accessing their services.

Qualitative interview process

We conducted qualitative interviews and focus groups using yarning[26] (interview-yarns and yarning circles) with healthcare providers, managers, and data and informatics staff from a diverse range of APHSs across metropolitan, regional and remote locations nationally, and representatives from key government and non-government agencies involved in dementia and primary healthcare data and research. Participants were recruited through the project team's professional networks and by drawing on the networks of participants. A semi-structured interview-yarning schedule (Appendix 2) was developed to elicit participants' knowledge and experiences in relation to MCI and dementia diagnoses, health record keeping, barriers and enablers to data collection, availability and quality of data on MCI and dementia diagnoses, and data needs and opportunities to improve the quality of data available in relation to Aboriginal and Torres Strait Islander peoples living with MCI or dementia.

Transcribed interview-yarn data were analysed using both content analysis[28] and inductive reflexive thematic analysis.[29] Content analysis was used as a tool for identifying common issues and topics to be included in the design and development of the survey in Phase 2b. Reflexive thematic analysis was also used to acknowledge that the researchers played an active role in the construction of meaning of the participants' descriptions by contributing their expertise as healthcare providers and researchers with backgrounds in geriatric medicine, primary healthcare, public health and a common interest in optimising the health and wellbeing of Aboriginal and Torres Strait islander peoples at risk of or living with dementia, and their carers, and communities. Coded data were organised into themes and presented to the multidisciplinary project team, the DGG and RWG where they were discussed, refined and challenged in the context of existing theory and clinical practice.

3.7 Phase 2b: Cross-sectional survey

Objectives

- To explore current data collection practices i.e. recording clinical information among healthcare providers providing MCI and dementia care to Aboriginal and Torres Strait Islander clients.
- To explore barriers and enablers to MCI and dementia collection and use among APHS healthcare providers.
- To explore APHS healthcare providers' data needs and preferences in relation to Aboriginal and Torres Strait Islander peoples living with MCI or dementia accessing their services.

Cross-sectional survey process

We conducted a national cross-sectional online survey using Qualtrics software. Survey content was informed by themes from Phase 2a and organised into four sections: i) roles and settings, ii) cognitive assessment and diagnosis, iii) existing data collections and uses, and iv) data needs and opportunities. The final survey instrument can be found in Appendix 3. The draft survey was reviewed by the RWG and piloted with two APHS staff.

The survey was distributed to 155 APHSs nationally via an email invitation that was distributed to a custom mailing list developed by the project team by collating publicly available APHS and representative staff emails from the National Aboriginal Community Controlled Health Organisation (NACCHO) service list and a list of IAHP-funded services that report to the OSR provided by the DHDA. The intended respondents were managers, senior healthcare providers and data or informatics staff working in APHSs and our participant inclusion criteria were stipulated in the survey preamble. Recipients were encouraged to share the survey link with relevant staff. Multiple respondents per service were permitted to participate, to explore diverse perspectives on MCI or dementia data in APHSs.

Respondent surveys in which demographic data and at least one service-based question was completed were included in the analysis. Data were analysed using descriptive statistics. Aggregated results are presented using bar charts and pie charts. Bar charts are presented as "number" on the Y-axis in increments of two and pie charts are presented in percentages.

3.8 Phase 3: Expert panel workshop

Objectives

- To integrate and interpret findings from Phase 1, 2a and 2b.
- To refine a set of recommendations for improving the availability and quality of MCI and dementia data among Aboriginal and Torres Strait Islander peoples to present to the AIHW.

Expert panel workshop process

Analyses from the desktop review, interview-yarns, yarning circles and the survey were combined to generate a set of preliminary recommendations. We then convened a full-day workshop to seek expert input into, and refinement of, the preliminary recommendations. Workshop participants were identified and invited through the professional networks of the project team, DGG, RWG and AIHW NCMD, and included a diverse expert panel from across Australia, comprising:

- Aboriginal and Torres Strait Islander researchers and healthcare providers.
- Health service staff from APHSs including general practitioners (GPs) and geriatricians.
- Academic and policy makers with expertise in data, data governance and data sovereignty.
- Government and governance leaders including representatives from Aboriginal and Torres Strait Islander health services peak bodies.

Following a presentation of project findings, group discussion was co-facilitated by the research team to solicit feedback on the draft recommendations. Discussion of each recommendation was guided by the same questions:

1. Is the recommendation clear?
2. Does the recommendation align with the evidence we have presented?
3. Does the recommendation fit within your knowledge or expertise? Anything to change or add?
4. Do you have suggestions for implementation?

Data generated in the workshops comprised in-depth researcher notes and memos documenting the content of discussions. Researcher notes and memos were analysed using framework analysis, where workshop data were summarised and mapped to each of the draft recommendations as pre-defined categories, whilst also allowing additional insights or new recommendations to be identified.[30]

See Appendix 1 for a detailed description of the methodology and methods.

4. RESULTS

4.1 Project 1 – Desktop review

Key finding: Our desktop review of the literature identified that there are currently no resources or dementia data collections based on direct reports from APHSs.

The advanced Google search and AIHW and ABS site search identified two relevant grey literature resources that reported on dementia prevalence in Aboriginal and Torres Strait Islander populations: The AIHW Dementia in Australia 2025[31] report and the ABS Census 2021.[32] The AIHW Dementia in Australia 2025 report describes the results of smaller studies that provide indications of:

- The prevalence of dementia in the Northern Territory,[33] the Kimberley region of Western Australia[10, 34] and the Torres Strait and Northern Peninsula Area of Far North Queensland.[35]
- Urban and regional differences in dementia among community-dwelling older Aboriginal Australians in New South Wales.[36]

The ABS Census 2021 included a question where respondents could self-report having dementia.

The limited number of in-scope, publicly available grey literature resources identified informed our decision to perform citation searching, scientific database searching and to include academic literature to provide a more holistic view of the dementia data landscape. Academic database and citation searching identified 15 relevant studies reporting prevalence data (Table 1) including:

1. One study in an ACCHO primary healthcare setting (a researcher-led audit of individual health records – see Box 3);[37]
2. Seven community-based studies that collected primary data in selected Australian jurisdictions and; [10, 34-36, 38-40]
3. Seven studies that used existing data sources including hospital admissions, primary healthcare, aged care services, death records, health check data and ABS data. [2, 6, 41-44]

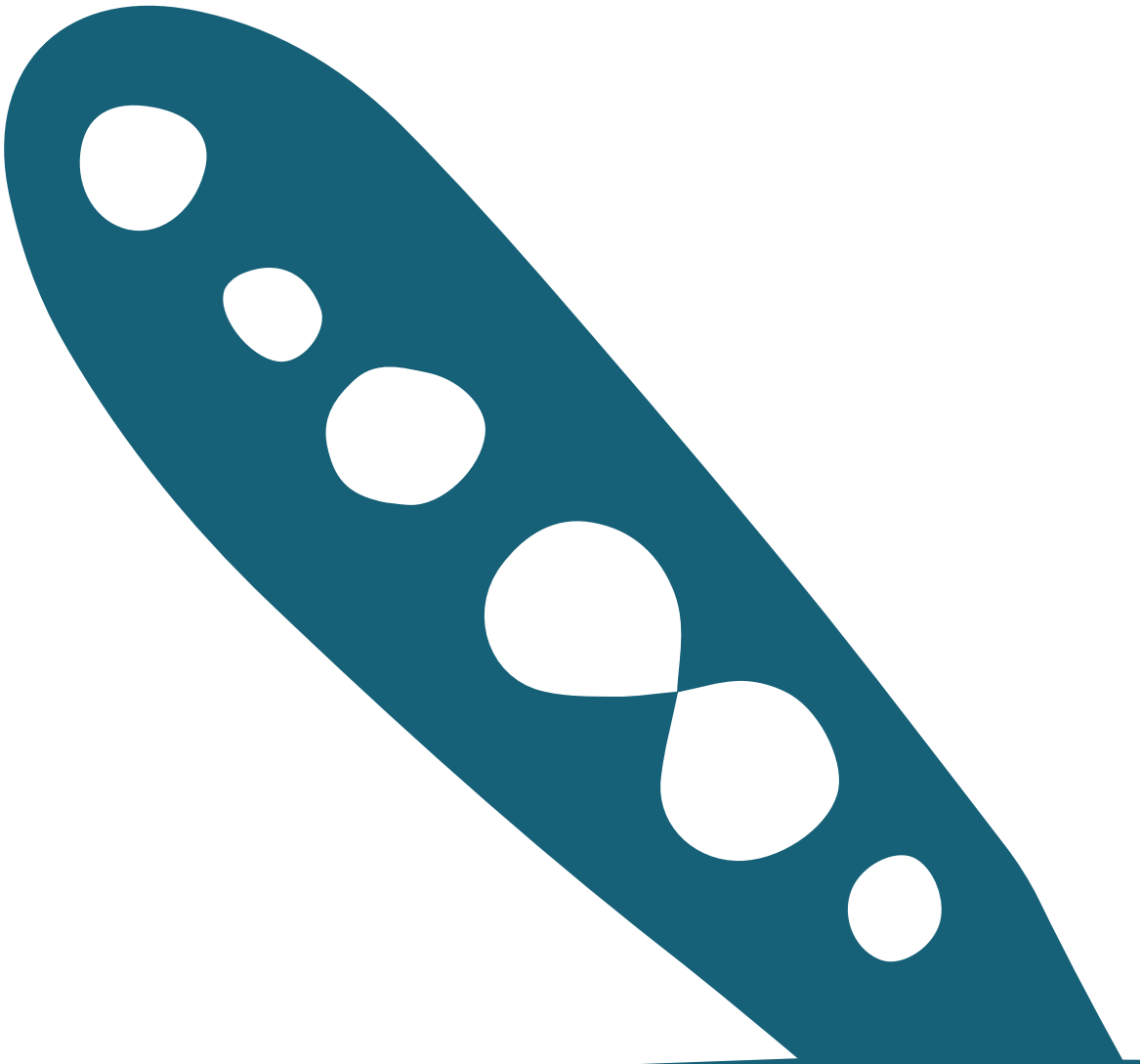
Table 1. Resources identified in desktop review

Reference (first author, year, title)	Study aim	Setting	Aboriginal and Torres Strait Islander Participants	Data collection	New or existing data source
Academic studies					
Smith et al. 2008. High prevalence of dementia and cognitive impairment in Indigenous Australians.[10]	To determine prevalence of dementia and cognitive impairment in older Indigenous Australians.	Kimberley region, Western Australia	363	Cognitive screening assessments using the Kimberley Indigenous Cognitive Assessment (KICA) tool and review by specialist clinicians.	Newly collected data
Li et al. 2014. Dementia prevalence and incidence among the Indigenous and non-Indigenous populations of the Northern Territory.[33]	To estimate dementia prevalence and incidence in NT Indigenous and non-Indigenous populations.	Northern Territory	311 (Indigenous)/ 473 (non-Indigenous)	Capture-recapture method using four Northern-Territory-based data sources (hospital admissions, primary healthcare, aged care services, death registration). The number of dementia cases contributed by the primary healthcare dataset was not reported separately.	Existing administrative data
Radford et al. 2015. Prevalence of dementia in urban and regional Aboriginal Australians.[36]	To determine prevalence of dementia in urban and regional Aboriginal communities.	Mid-North New South Wales	336	Structured interviews, cognitive screening assessments, detailed medical assessments and clinical reviews.	Newly collected data
LoGiudice et al. 2016. Incidence and predictors of cognitive impairment and dementia in Aboriginal Australians: a follow-up study of five years.[34]	To determine prevalence of dementia and cognitive impairment in older Indigenous Australians.	Kimberley region, Western Australia	189 (of 363 participants in original study, Smith 2008)	Clinical assessment using a comprehensive culturally appropriate cognitive assessment tool (KICA).	Newly collected data
White et al. 2019. The prevalence of cognitive impairment among people attending a homeless service in Far North Queensland with a majority Aboriginal and/or Torres Strait Islander people.[40]	To identify cognitive impairment prevalence in cohort attending a homelessness service.	Far North Queensland	60 (45/60 Indigenous)	Interview-administered cross-sectional survey, cognitive assessments using KICA and clinical diagnosis by a psychiatrist, and the 36-item version of the World Health Organisation Disability Assessment Survey 2.0 (WHODAS 2.0).	Newly collected data
Strivens et al. 2020. Dementia prevalence in Torres Strait communities: Epidemiology / prevalence, incidence, and outcomes of MCI and dementia.[38]	To examine dementia prevalence and associated risk factors.	Torres Strait and Far North Queensland	322	Comprehensive diagnostic geriatric assessment to establish consensus diagnosis.	Newly collected data

Russell et al. 2021. Prevalence of dementia in the Torres Strait.[35]	To examine dementia prevalence and age-related problems.	Torres Strait and Far North Queensland	276	Comprehensive health assessment and a geriatric assessment, used to establish consensus diagnosis.	Newly collected data
Waller et al. 2021. Deaths with dementia in Indigenous and non-Indigenous Australians: A nationwide study.[41]	To compare rates and coding of dementia mortality between Indigenous and non-Indigenous Australians.	National	1,148 (Indigenous)/1,201 (Not stated)	Dataset of all registered deaths in Australia for the years 2006 to 2014 from the Australian Coordinating Registry of Births, Deaths and Marriages.	Existing administrative data
Temple et al. 2022. Demographic drivers of the growth of the number of Aboriginal and Torres Strait Islander people living with dementia, 2016–2051.[6]	To examine demographic drivers in growth of dementia in Aboriginal and Torres Strait Islander peoples.	National	N/A – Projection study	Data prepared by the Australian Bureau of Statistics (ABS) on births, deaths, migration and identification change. Australian Institute of Health and Welfare estimates of dementia prevalence.	Existing administrative data – projected estimates
Lavrencic et al. 2022. Dementia incidence, APOE genotype and risk factors for cognitive decline in Aboriginal Australians.[39]	To identify dementia incidence and risk factors in Aboriginal Australians residing in urban areas.	Mid-North New South Wales	155 (336 baseline participants)	Structured interviews, cognitive screening, medical assessment, consensus panel review for diagnosis and collection of genotypes.	Newly collected data
Bradley et al. 2025. Detection of cognitive impairment, dementia and associated risk factors among Aboriginal and Torres Strait Islander peoples: Retrospective baseline audit results from a stepped-wedge cluster-randomised controlled trial.[37]	To identify documented dementia, cognitive impairment not dementia (CIND) and associated risk factors in individual health records.	12 ACCHOs in four states; Queensland, Western Australia, Victoria and New South Wales	1655	A study-specific tool used by researchers to audit medical individual health records of clients aged 50 years or older from 1 September 2016 to 31 January 2019 across 12 ACCHOs.	Extracted clinical data (refer to Box 3)
Clarke et al. 2025. The intersection of rurality and dementia prevalence in Australia for Aboriginal and Torres Strait Islander and non-Indigenous peoples.[42]	To identify dementia prevalence as it intersects with rurality.	National	People 45+ who responded to the 2021 Australian census (187,952 Indigenous)	Nationwide respondent-reported ABS census data (2021).	Existing administrative data
Luke et al. 2025. Older Aboriginal and Torres Strait Islander populations living with dementia: State and territory scenario-based projections into the future.[43]	To estimate the number of Aboriginal and/or Torres Strait Islander people living with dementia within Australia disaggregated by state and territory to mid-century.	National	N/A – Projection study	ABS Statistics Census data (2011, 2016 and 2021), modelling from prevalence rates reported in a Kimberley dementia cohort study and self-reported rates from the 2021 Census.	Existing administrative data – projected estimates

Luke et al. 2026. Ageing of the Kimberley Aboriginal population and indicative estimates of the number of people living with dementia 2021-51.[44]	To examines ageing and dementia for Aboriginal people in the Kimberley 2021–51	Kimberley region, Western Australia	N/A – Projection study	ABS Census data (2011, 2016 and 2021), modelling from prevalence rates reported in a Kimberley dementia cohort study and self-reported rates from the 2021 Census.	Existing administrative data – projected estimates
Grey literature – Government reports					
AIHW. 2025. Dementia in Australia.[31]	To provide a comprehensive picture of dementia in Australia, including dementia prevalence, burden of disease, deaths and expenditure.	National	N/A	Prevalence estimate based on academic studies.	Existing research and administrative data

The availability of clinical information (data) depends on how information is recorded within CISs. Dementia-related data is documented in structured fields and as free-text. Recording practices affect how readily data can be identified, extracted and used. Box 3 describes a case study in dementia data collection in ACCHOs that demonstrates the variability and complexity of identifying and extracting dementia data in a primary healthcare setting.



Box 3: Let's CHAT Dementia - a case study in dementia data collection in primary healthcare

From 2018 to 2023, the *Let's CHAT Dementia* study carried out six-monthly detailed audits of dementia and dementia-related information in individual health records of more than 1,600 people aged 50 years and over in 12 Aboriginal Community Controlled Health Organisations (ACCHOs) in New South Wales, Queensland, Victoria and Western Australia, with representation from metropolitan, regional and remote settings.

Four clinical information systems (CISs) were used across the 12 ACCHOs. No standardised way of recording cognitive impairment and dementia diagnoses in medical records was identified. Whilst performing audits of individual health records, use of the search function within CISs yielded very few results. There were fewer than 10 results from searching over 2,000 records using the terms 'dementia' or 'cognitive impairment' (which, at 0.5%, is a fraction of the known prevalence). For this reason, it was necessary to perform a detailed (manual) audit of each medical record to discover any information about possible or confirmed cognitive impairment or dementia for people in the sample. This included reviewing free text in detail of individual consultations (progress notes), correspondence (including referrals, often scanned into health records), investigations, medications, specific assessment procedures (e.g. annual health checks and cognitive assessments) and other parts of the health record. The procedures in the table below were developed by the Let's CHAT Dementia team to guide the search for documentation of cognitive concerns or a diagnosis of cognitive impairment or dementia in the CISs used across the 12 ACCHOs.

Summary: The audits were time- and resource-intensive, only feasible for the contained period of the study and necessary to obtain an accurate picture of documentation practices. Although this process enabled a better understanding of the scope of what was discoverable in a medical record regarding cognition and dementia, it is not recommended as usual audit or reporting practice.

Clinical Information System			
MMEx	**Best Practice**	**Medical Director**	**Communicare**
1. Check 'Medical history' and 'Bio' page for a diagnosis of dementia or related term (e.g. cognitive impairment, MCI) 2. Go to 'Clinical summary'. Use the search function to search the terms: *dementia, confusion, delirium, memory, forgetfulness, cognitive, geriatrician, KICA, CT head, CT brain.* 3. Check in 'Documents' for referrals to a geriatrician or an ACAT assessment 4. Go to 'Management Plans'. If a GPMP is in place, check for any mention of dementia/ cognitive impairment. 5. If an 'Aboriginal Health Assessment' has been completed, check for any information regarding cognition. 6. If a 'Mental health assessment' has been completed, check for any information. regarding cognition.	1. Check 'Enhanced Primary healthcare' > 'Dementia Assessment 2. Check 'Past history' for a diagnosis of dementia or other (e.g. cognitive impairment, MCI) 3. Go to the progress notes and scroll through the consults for the audit period to check for any mention of *dementia, confusion, delirium, memory, forgetfulness, cognitive, geriatrician, KICA, CT head/brain, etc.* 4. Check in 'Correspondence out' for referrals to a geriatrician or an ACAT assessment. 5. If a GPMP is in place, check for any mention of dementia/ cognitive impairment. 6. If an 'Aboriginal Health Assessment' has been completed, check for any information regarding cognition. 7. If a 'Mental health assessment' has been completed, check for any information regarding cognition.	1. Check 'Medical history' for a diagnosis of dementia or other (e.g. cognitive impairment, MCI) 2. Go to the progress notes and scroll through the consults for the audit period to check for any mention of *dementia, confusion, delirium, memory, forgetfulness, cognitive, geriatrician, KICA, CT head/brain, etc.* 3. Check in 'Letters' for referrals to a geriatrician or an ACAT assessment. 4. If a GPMP is in place, check for any mention of dementia/cognitive impairment. 5. If an 'Aboriginal Health Assessment' has been completed, check for any information regarding cognition. 6. If a 'Mental health assessment' has been completed, check for any information regarding cognition.	1. Check 'Main summary', 'Medical history' for a diagnosis of dementia or other (e.g. cognitive impairment, MCI) 2. Go to the progress notes and scroll through the consults for the audit period to check for any mention of dementia, confusion, delirium, memory, forgetfulness, cognitive, geriatrician, KICA, CT head/brain, etc. 3. Go to the 'Details' section, search under 'Documents' for referrals to a geriatrician or an ACAT assessment. You can do a search for dementia, geriatrician, memory to help you locate a specialist letter if present. 4. If a GPMP is in place, check for any mention of dementia/ cognitive impairment. 5. If an 'Aboriginal Health Assessment' has been completed, check for any information regarding cognition. 6. If a 'Mental health assessment' has been completed, check for any information regarding cognition.

ACAT, aged care assessment team; CT, computerised tomography; GPMP, general practitioner management plan; KICA, Kimberley Indigenous Cognitive Assessment; MCI, mild cognitive impairment

4.2 Project 2a – Qualitative key informant study

4.2.1 Participants and demographics

Between June 2025 and October 2025, 28 key informants participated in 10 interview-yarns and two yarning circles. Interview-yarns ranged from 34 to 71 minutes, with an average length of 50 minutes, whilst the yarning circles lasted between 59 and 82 minutes. Participants represented diverse cultural and professional backgrounds including Aboriginal and/or Torres Strait Islander and non-Indigenous APHS staff (senior managers, GPs, nurses/nurse practitioners, data, informatics and research staff, public health medical officers, physiotherapists, Aboriginal health workers/health practitioners and geriatricians). Of the 28 key informants, 22 represented seven APHSs from remote, regional and metropolitan locations across Western Australian, Queensland, New South Wales, Australian Capital Territory and Victoria. Although no services from Tasmania or Northern Territory were included, a representative from NT Health participated. Additional key informants included representatives from NACCHO, senior researchers from the Australian Dementia Network Registry, and state and territory government health department staff.

4.2.2. Overarching findings and key themes

Key findings:

- MCI and dementia data is not systematically collected and data quality in APHSs is poor.
- Poor data quality is related to the complexity of dementia as a health condition as well as multidimensional and interrelated factors identified at the health system, health service, healthcare provider and Community-individual level (Figure 4).
- Dementia data needs and preferences of key informants centred around implementing strong data governance frameworks and ensuring the value and usefulness of dementia data for APHSs.

We have summarised the findings alongside anonymised, illustrative quotes.

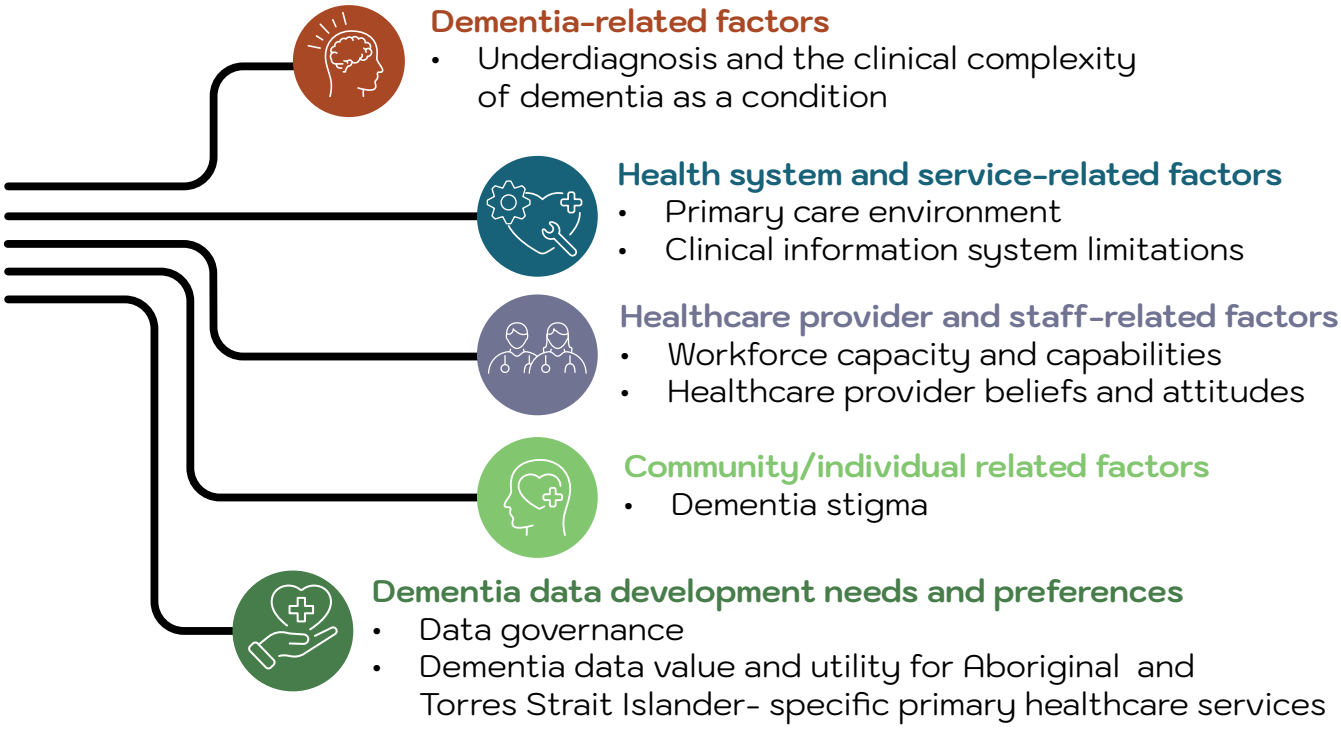


Figure 4. *Summary of qualitative findings*

Dementia-related factors

Underdiagnosis and clinical complexity of dementia as a health condition

Under-detection and underdiagnosis of MCI and dementia were recognised by all participants as being at the core of poor dementia data quality. Participants described underdiagnosis as having cascading impacts and implications across the whole primary healthcare data journey, ultimately limiting how those data can be used, both internally within services and externally for research and reporting:

> *"There's no point having a reporting mechanism if you don't have the clinical practice that identifies the cognitive impairment"* – Participant 1.

Participants emphasised the clinical complexity of dementia and the diagnostic process as multifaceted and time-intensive, usually requiring extended and repeated consultations over long periods of time. Longer and multiple consultations were seen as challenging in the context of high need-demand and long waitlists. Some healthcare providers described that signs and symptoms of cognitive impairment may be due to other conditions creating diagnostic ambiguity. This diagnostic complexity and uncertainty that primary healthcare providers felt in making a clinical diagnosis, was often described as challenging in the absence of a single diagnostic test for dementia:

> *"… As a medical profession, we're not even scratching the surface on diagnosing dementia. That may change with blood-based biomarkers down the track, but at the moment we're not diagnosing it well, clinically."* – Participant 6a.

Health system and service-related factors

Primary healthcare environment

The primary healthcare context of competing priorities and resource constraints was described by many participants as making MCI and dementia diagnosis challenging. Many clients present with complex health needs and social circumstances and health providers described needing to "put out all the fires" or manage multiple, more immediate clinical concerns that took precedence over the assessment of cognition and chronic diseases like dementia:

> *"We're not even close to putting the fires out, let alone doing seriously important chronic disease work; all the preventive work – everything that needs to be done and should be done to provide really good healthcare"* – Participant 4.

These competing demands also limited healthcare providers' capacity to consistently complete annual health checks, including case finding questions about memory and thinking recommended for clients aged over 50 years. Most participants working in APHSs mentioned the lack of standardised processes for cognitive assessments and dementia diagnoses, noting considerable variation in how and when assessments were undertaken. Competing priorities in the primary healthcare environment also created barriers to service staff's ability to use data internally or to engage in other data-related activities beyond direct clinical care.

A lack of established referral pathways and limited access to specialist cognition services, such as memory clinics and geriatricians that are required to support timely and accurate dementia diagnosis, were also noted as critical contributing factors to the underdiagnosis of dementia:

> *"We can't diagnose dementia here because we don't have the clinicians to do it, and that's the challenge, and that's why you're not going to get your data [with] any accuracy in these regions. Because there's not enough geriatricians, there's no incentive to come here as a geriatrician, because there's no services with geriatrics. And then beyond that, the diagnostic pathway, it's relying on some wonderful select GPs… which are…over-worked and stressed" – Participant 10.*

> *"If you're somewhere like [service] where we don't actually have a geriatrician, we don't have anyone who can actually do that diagnosis, that's a little bit of a worry because we've got so many people that potentially are undiagnosed. The statistics aren't going to be as accurate as we need them to be"* – Yarning Circle 1 Participant.

The importance of culturally safe models of care, for example multidisciplinary care teams where specialist cognition services are integrated within APHSs, were emphasised as a key mechanism for supporting earlier detection and diagnosis of dementia.

Many participants described the transient workforces and high staff turnover in primary healthcare, including a reliance on locum doctors in some settings. This is disruptive to continuity of care, making it difficult for healthcare providers to recognise changes in cognition over time. A transient workforce was also seen to undermine the development of trusted, ongoing relationships between healthcare providers and clients. Having established relationships was identified by participants as essential to being able to initiate sensitive conversations about cognition. Finally, frequent staff changes and the need for locum providers to work across multiple CISs were seen to compromise the accuracy and completeness of health records, further creating barriers to accurate health record keeping:

> *"We have a workforce problem throughout our sector, but particularly as we get more remote, we're more dependent on locums, and those people are less likely to get to know the system and to appreciate the importance of collecting structured data. And so those people are more likely to be free texting and creating some problems"* – Participant 10.

Clinical information system limitations

Many participants noted the inconsistency in how and where dementia-related information is documented within health records, and that current limitations in the CISs being used impede accurate and consistent health record keeping. In the absence of standardised health record keeping, structured MCI and dementia data fields, and data coding processes, healthcare providers described that primary healthcare providers frequently relying on free text to record MCI and dementia information. While this may capture relevant clinical information narratively, it significantly limits the availability of discoverable data and the ability to extract and report on dementia in a systematic way:

> *"Every dataset has different indicators of quality…when we talk about quality, we're talking about completeness, and whether the diagnosis of dementia was standardised or consistent... [in the] dataset, which is not happening right now"*– Participant 7.

The main CIS limitations identified were poor intraoperability i.e. the ability to consistently capture and retrieve data within a single health record or CIS and poor interoperability i.e. the ability to share and communicate data across CISs, services, systems and sectors. Poor intraoperability means that dementia-related information is recorded inconsistently or dispersed across multiple locations within a health record. The dementia diagnostic process also often requires clients to move and receive care between primary, specialist, acute and aged care settings, and in the absence of interoperable systems, critical information about cognitive assessments, investigations, diagnoses and care plans are frequently lost or inaccessible across the care continuum:

> *"The complexity of which system you put data into and how they talk to each other or don't talk to each other has quite a significant impact on whether people can access that data, whether it works well for you, and you don't always have that ability to just throw bucketloads of money at the newest, biggest system that will integrate everything magically and put it all at your fingertips"* – Yarning Circle 2 Participant.

> *"The things that influence the quality of data that is coming into the system, the first is about the clinical information system itself, and what is the capacity of that system to collect good quantitative data…and to what extent can you locally adapt the system to meet your needs. The second is about the clinician's awareness of what is good quality information and how to record that…moving away from free texting and into structured data. And where to go within the system to enter that information and whether it's within workflows."* – Participant 10.

Healthcare provider and staff-related factors

Workforce capacity and capabilities

Participants described considerable variability in the clinical knowledge and skills of healthcare providers in recognising signs and symptoms of MCI and dementia, and in adhering to best-practice clinical guidelines for dementia care for Aboriginal and Torres Strait Islander peoples:

> *"In terms of diagnosis, you need the referral, and someone needs to make the diagnosis. And there's such a varied skillset within general practice."* – Participant 5.

In services where access to education and training on best-practice dementia care was available, key informants reported that health providers felt more comfortable raising and discussing cognition, administering appropriate cognitive assessment tools, and making and recording dementia diagnoses within the primary healthcare setting. Despite this, challenges in delivering ongoing education and training to ensure staff were consistently and appropriately skilled were also highlighted:

> *"[We] rolled out three educational webinars about dementia diagnosis and care, so all the staff at our practice receive that. Although some of those staff have now left or are on leave, and we've got new staff that haven't received that practice; that's one of the issues in Aboriginal Medical Services generally, the nature of staff coming and going"* – Participant 6b.

Participants also identified gaps in data literacy among healthcare providers, which shaped their understanding of the links between how clinical information is recorded in the health record and being able to generate data (discoverability) as well as limited understanding of the value of data:

> *"I think there needs to be a better awareness in general practice training, and across services, about data collection. And particularly the sector. I think the sector's been a bit slow on that"* – Participant 4.

> *"We're always trying to work on teaching GPs about how we can use the [clinical information system] better. For example, if it's only recorded in clinical notes then there's no way to extract that"* – Yarning Circle 2 Participant.

> *"It's very much garbage in, garbage out. If people don't record the data, there's nothing we can do other than continue to encourage them, make it easier, make it simpler, find out why they're not"* – Yarning Circle 1 Participant.

Services with access to dedicated data or informatics staff or teams had greater capacity to engage in internal data use and to prioritise a 'data-driven approach', and some participants suggested that access to external data support (organisations or individuals who could provide data coding and analysis) could further enhance services' ability to use data internally or externally.

Healthcare providers beliefs and attitudes

Alongside clinical capabilities, participants highlighted the influence of healthcare providers' beliefs and attitudes towards dementia diagnoses and the value of dementia data. They described a strong sense of 'clinical inertia' among healthcare providers that was underpinned by fatalistic beliefs about the value of diagnosing dementia. For example, some healthcare providers perceived there to be little benefit in making a dementia diagnosis when culturally meaningful post-diagnostic care options were limited or unavailable:

> *"What do you do if you don't have the resources to help?"* – Participant 4.

This fatalism extended to views on dementia data, with some participants suggesting that improving the quality or completeness of MCI and dementia data would not necessarily translate into improved health outcomes for Aboriginal and Torres Strait Islander peoples given the current limitations of the healthcare and support systems:

> *"Data is better when people feel like there is something you can do once you've made a diagnosis. You know, there's clinical inertia, there's inertia in the population itself, because of what the meaning of the diagnosis means, and the lack of a cure. And so, the way to increase diagnoses is to have, really, safe, culturally appropriate diagnostic and care pathways that have meaning for people, that they go, "I want that."* – Participant 6a.

Similarly, participants emphasised that staff buy-in around more accurate health record keeping was critical for strengthening internal processes and supporting more systematic data collection practices.

Community related factors

Dementia stigma

Fatalism, shame and stigma around dementia, both within the Community and the healthcare sector, were described as a barrier to individuals seeking or engaging with primary healthcare services about concerns related to memory and thinking. One participant explained the fatalism and stigma associated with receiving a dementia diagnosis:

> *"They're getting told, 'you're going to die soon…Give up life, there's nothing to look forward to"* – Yarning Circle 2 Participant.

Another reflected on how dementia stigma extends to the healthcare sector*:*

> *"Speaking to the Community… there's always individuals who don't want to be asked [about cognition] right? But I also think people feel that we've been a bit neglectful…in First Nations health...it's been a bit taboo to talk about it, when actually people may want to talk about it because they want support for their Elders and for the vulnerable…we've just not been proactive enough"* – Participant 4.

Dementia data development needs and preferences

Data governance

Participants emphasised the critical importance of strong, self-determined Aboriginal and Torres Strait Islander data governance frameworks as a prerequisite for any dementia data development initiatives, to ensure that data sovereignty principles are upheld. It was widely agreed that data governance structures and processes must be co-designed with APHSs so that Communities can retain ownership, control and access to their data:

> *"I guess also just the complexity of data sovereignty… especially when you're talking about data on people with dementia… I imagine there would be a lot of concern within the sector…. And also, as part of the sovereignty, what's given back to communities if they're providing data and things like that? I know, from every conversation about data that we have with the sector, it's people saying that, "they're always taking our data. We're always giving data and we never really get anything back."* – Participant 8.

Dementia data value and utility for Aboriginal primary healthcare providers

In relation to the value and utility of dementia data for APHSs, participants highlighted that any potential healthcare and health outcome benefits must outweigh the additional burden placed on services to collect or externally report MCI and dementia data. A key preference was for two-way data reporting, whereby data are returned to services in accessible, disaggregated formats that can directly inform internal service planning, workforce development, resource allocation and advocacy for additional funding:

> *"What use is the data serving… For other organisations where they're not able to have the kind of data that they could use for service planning and for understanding their own community needs, then that might be really helpful for them [to get the data back], but again at a disaggregated level"* – Participant 5.

Participants also expressed some initial support for the inclusion of a cognition-related nKPI, provided it was strengths-based, co-designed with services and focused on service processes rather than outcomes; the most commonly suggested example was an indicator capturing the number of cognitive assessments completed within each service.

4.3 Project 2b – Survey

4.3.1 Participants and demographics

The survey was distributed to 155 unique APHSs, with 78 people accessing the survey and 31 completing it, yielding a response rate of 20%. Respondents represented a diverse range of roles, including healthcare providers (GPs, geriatricians, nurses and Aboriginal health workers/health practitioners), case managers and service managers. Services were geographically diverse, spanning all states and territories except Tasmania and the Australian Capital Territory, and included metropolitan, regional and remote settings, with the majority located in regional or remote areas. Service sizes varied widely, with a median of 2,500 [interquartile range 250–4,800] Aboriginal and/or Torres Strait Islander clients per year, and an overall range from 15 to 15,000 clients annually. A majority of survey respondents were non-Indigenous, with 21 (70%) non-Indigenous, nine (30%) identifying as Aboriginal, and one not completing this survey question on identification. The services that respondents worked in were inner regional locations (36%), outer regional (29%), remote (26%) and metropolitan locations (10%) (Figure 5).

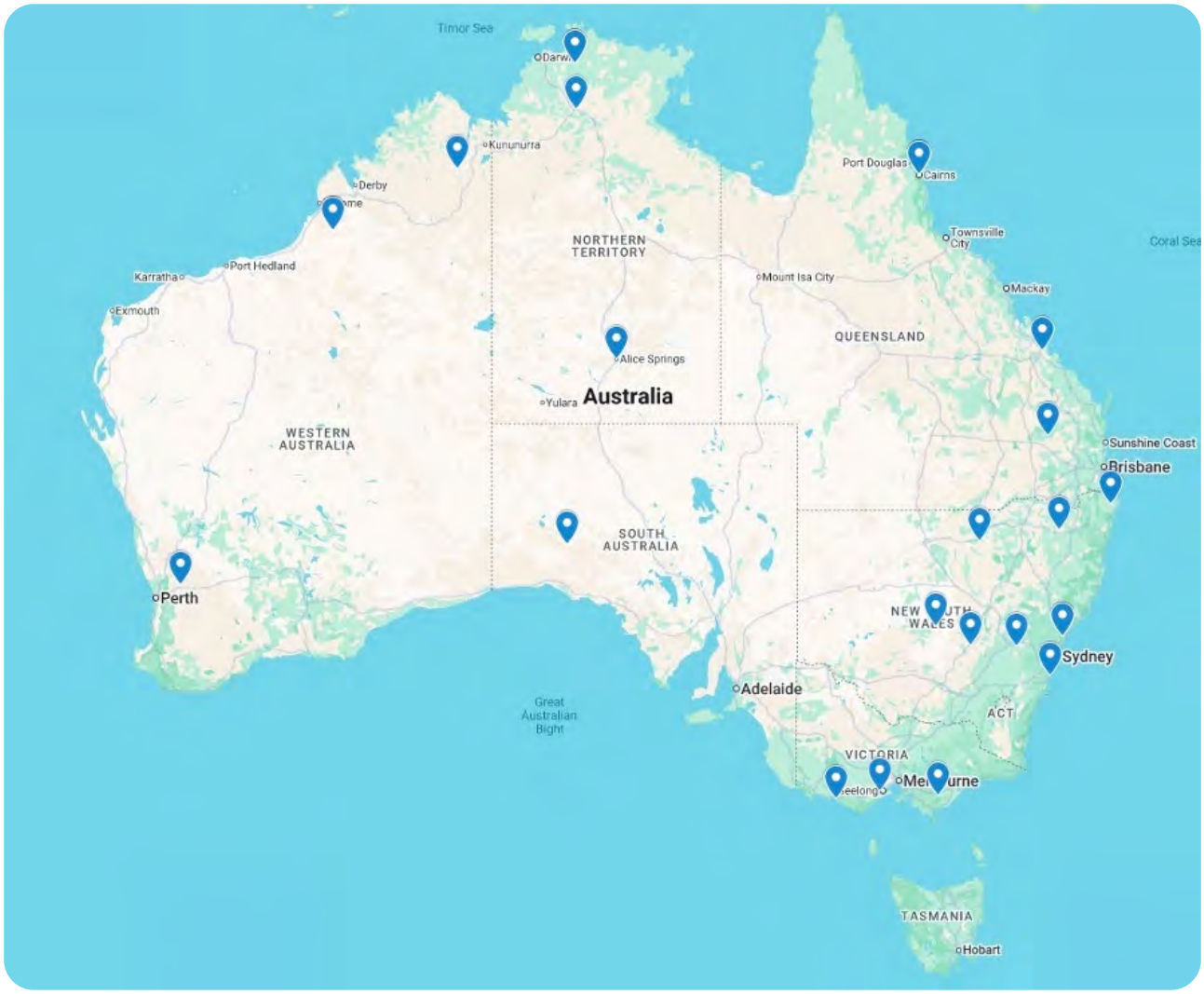


Figure 5. *Respondent service locations.*

4.3.2 Survey findings

Twenty-six respondents answered a question about routinely asking clients over the age of 50 years about their memory and thinking as part of annual health checks. Most respondents (n=16, 62%) reported that the service they worked for consistently and routinely asked questions about memory and thinking, with a minority of services (n=4, 15%) not routinely asking questions of clients about memory and thinking (Figure 6).

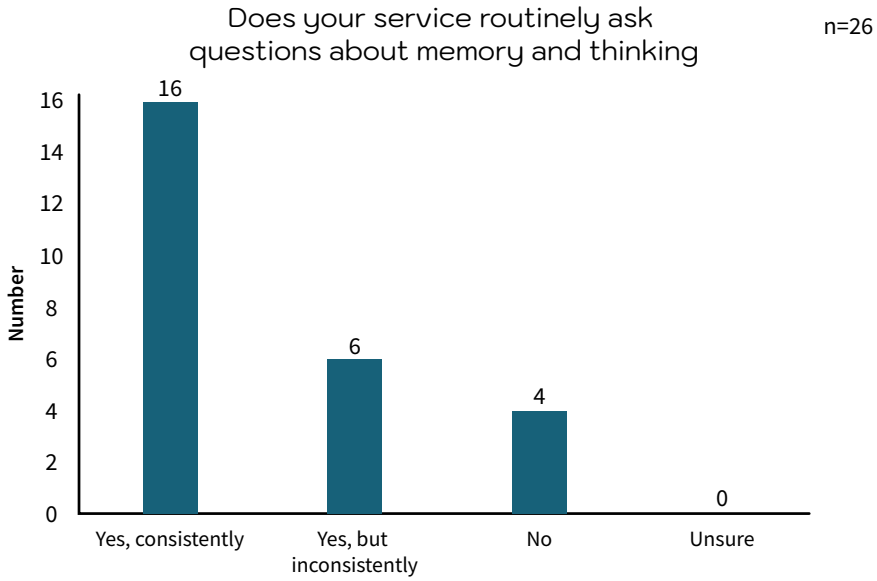


Figure 6. *Routinely asked questions about memory and thinking*

Twenty respondents answered a question about the cognitive assessment tool(s) used at their health service. The most commonly used cognitive assessment tool was the Mini-Mental Status Examination (MMSE) (n=14, 70%), followed by the Kimberley Indigenous Cognitive Assessment (KICA-Cog) and the Montreal Cognitive Assessment (MoCA) (both n=5, 25%) (Figure 7).

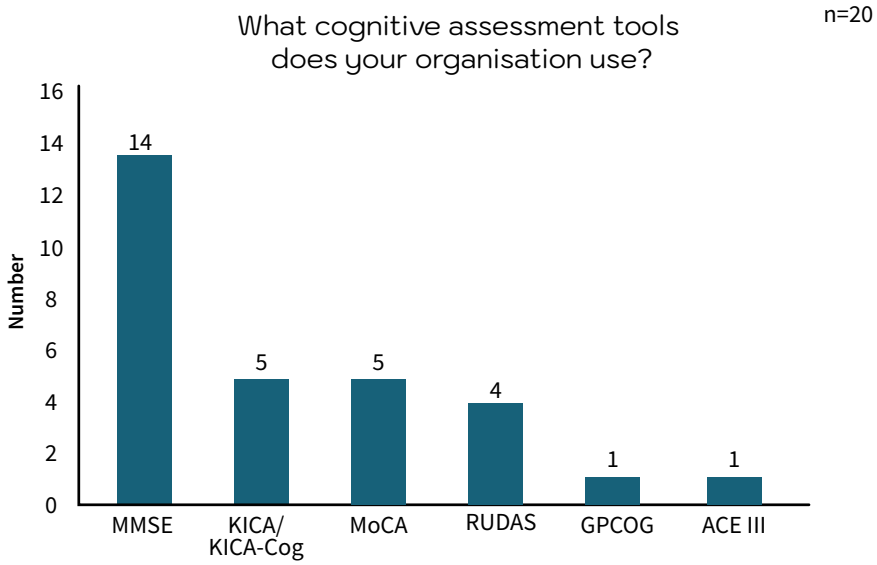


Figure 7. *Respondent report of which cognitive assessment tool is used in their organisation* KICA/KICA-Cog = Kimberley Indigenous Cognitive Assessment. MMSE = mini-mental status examination. MOCA = Montreal Cognitive Assessment. RUDAS = Rowland Universal Dementia Assessment Scale. GPCOG = General Practitioner Assessment of Cognition. ACEIII = Addenbrooke's Cognitive Examination.

Twenty-five respondents answered the question about the most important barriers to diagnosing dementia at their health services. Respondents could select up to five barriers. The most common barrier (n=16, 64%) identified was "complex social and health circumstances of clients." The least common responses (both n=1, 6%) were "clinician perceived lack of value in diagnosis," and "none - there are no barriers" (Figure 8).

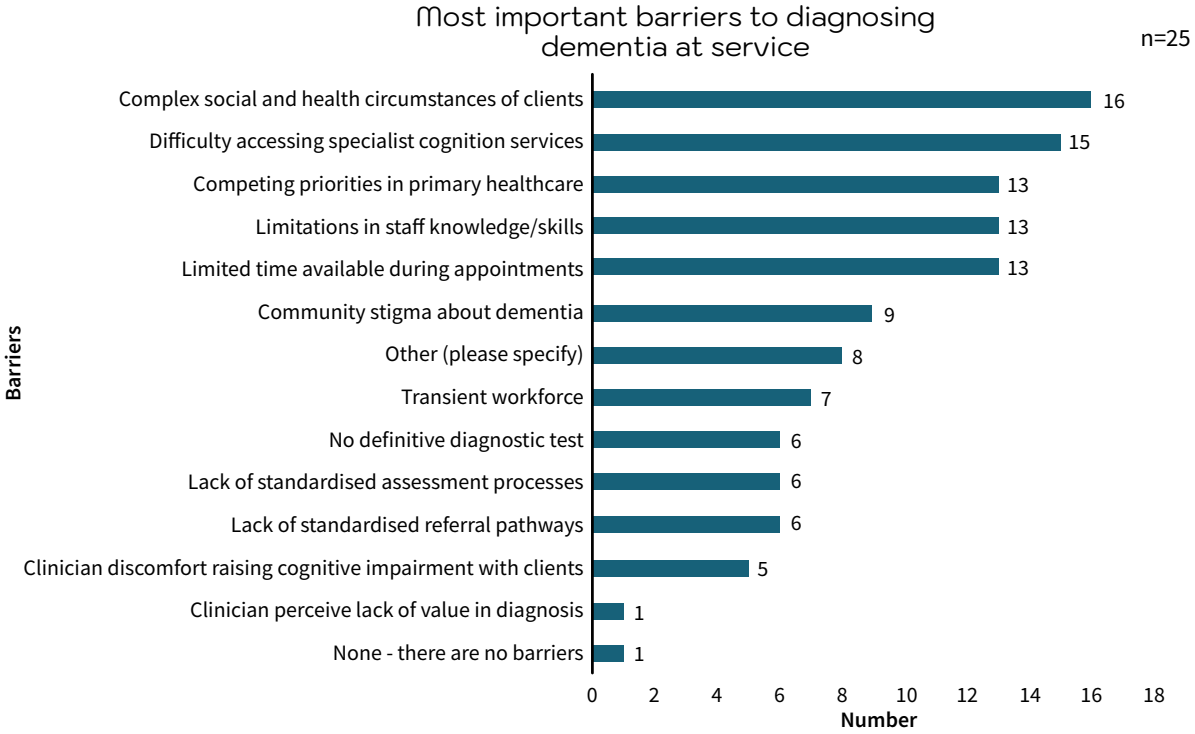


Figure 8. *Respondent report of barriers to diagnosing dementia at their health service*

Twenty respondents answered a question about recording MCI or dementia diagnoses in clinical software. Only 5% (n=1) of respondents reported that their health service does not routinely record cognitive diagnoses in clinical software, with 95% (n=19) reporting that cognitive diagnoses are recorded but with variable consistency and methods (Figure 9).

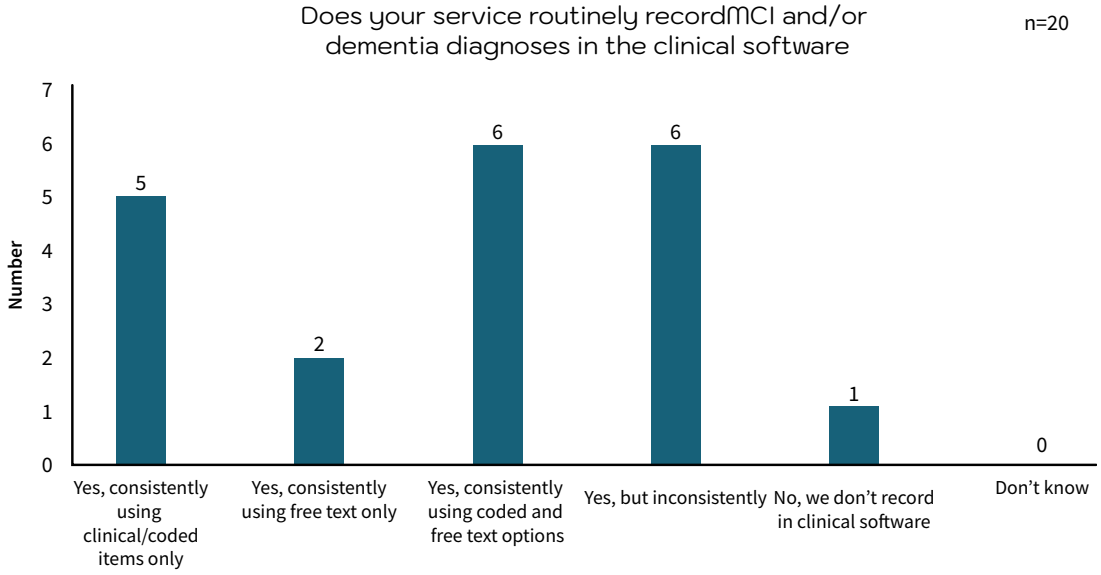


Figure 9. *Respondent report on whether health service routinely records cognitive diagnoses*

Twenty-six participants responded to a question about whether dementia-related data is used internally at their health service for purposes other than direct care. Just under half (n=11, 42%) reported that data is used only for direct client care (Figure 10).

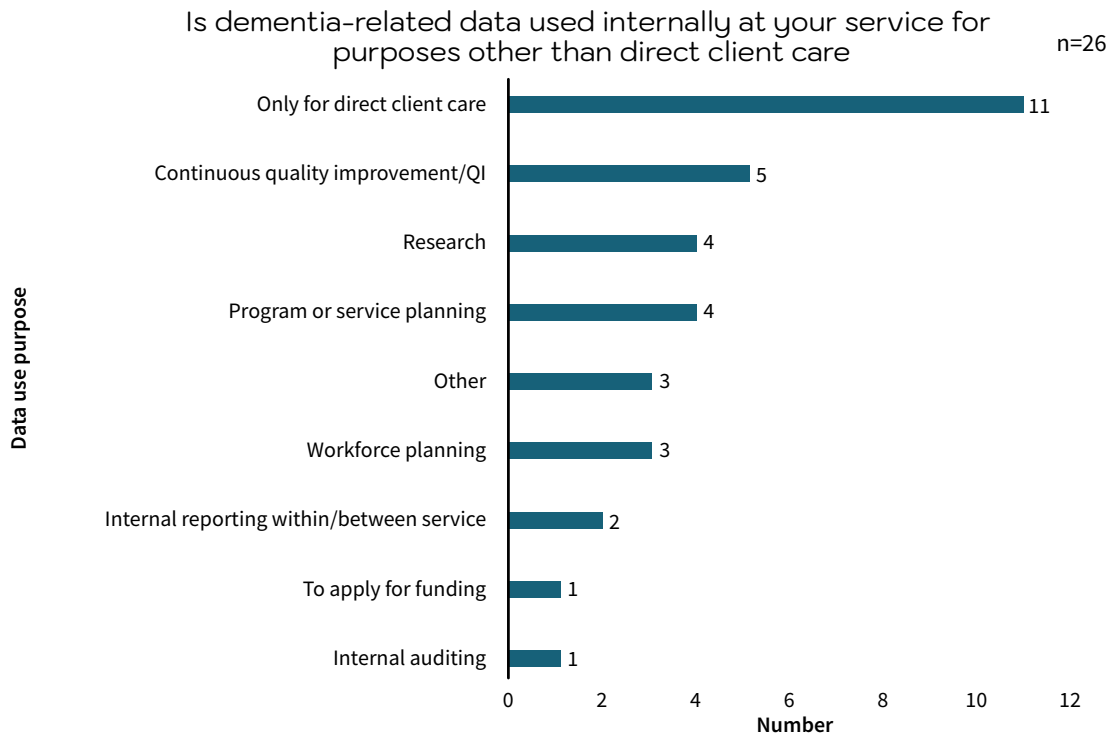


Figure 10. *Respondent report of whether dementia-related data is used internally at the health service for purposes other than direct client care.*

Twenty-two participants responded to a question about the challenges their health services experience when using dementia-related data. The most common responses (both n=12, 55%) were "dementia underdiagnosed" and "no dedicated staffing for data management" (Figure 11). Poor data quality (n=10, 45%) and difficulty tracking diagnoses across services (n=8, 32%) were also relatively common.

Figure 11*. Respondent report of the challenges their health services faces when using dementia-related data*

Twenty-three participants responded to a question asking what would be most helpful to support dementia diagnosis at their service. The most common support identified was "staff education and training" (n=14, 61%) (Figure 12). "Collaborative, multidisciplinary and interprofessional approaches to care" (n=12, 48%) "Community education" (n=10, 40%) and "funding specifically for dementia care and services" (n=10, 40%) were also commonly identified as being helpful to support dementia diagnoses in their service.

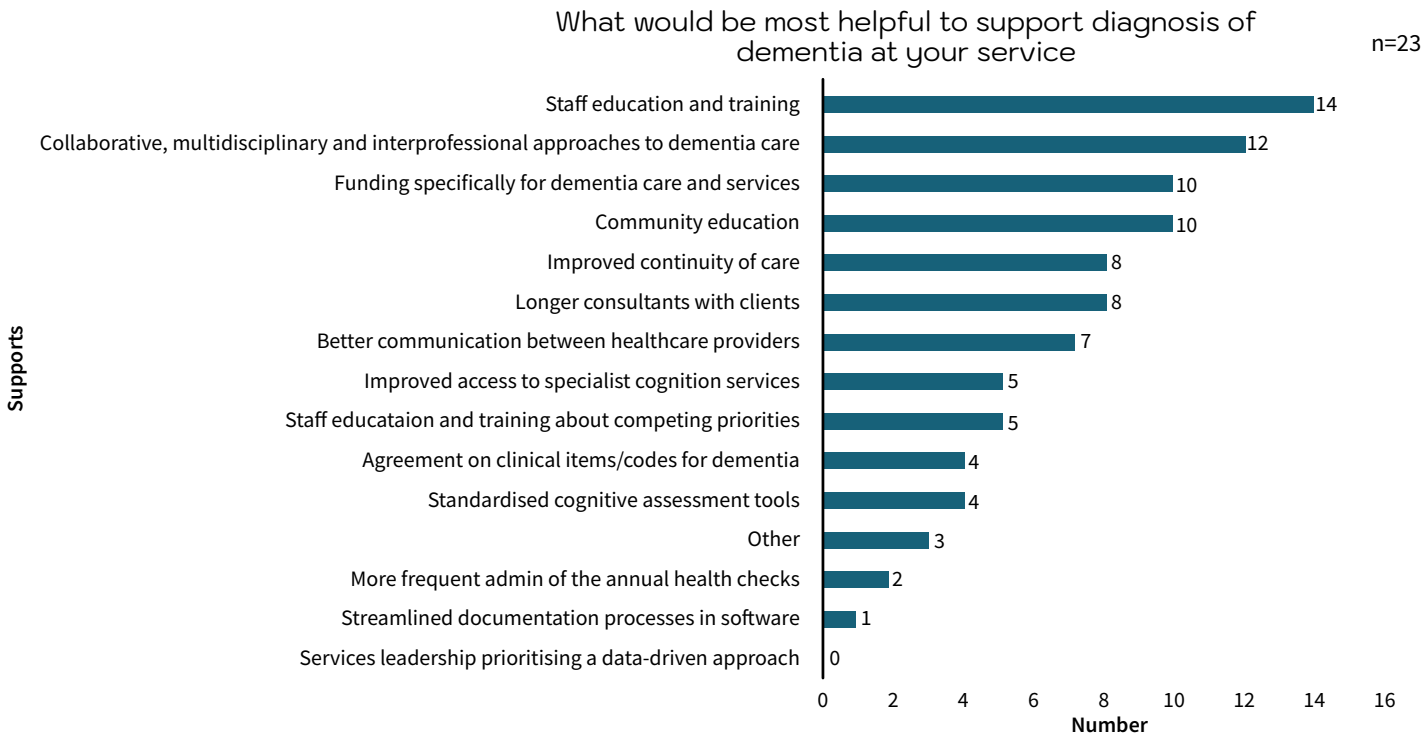


Figure 12. *Respondent report of what would be helpful to support dementia diagnosis at their health service*

Twenty-five participants responded to a question asking what would assist staff to use dementia-related data more effectively. The most common response was "education and training in dementia identification/assessment" (n=18, 72%) (Figure 13). "Clearer workflows or guidelines" (n=11, 44%) and "education on coding processes" (n=10, 40%) were also ranked as helpful.

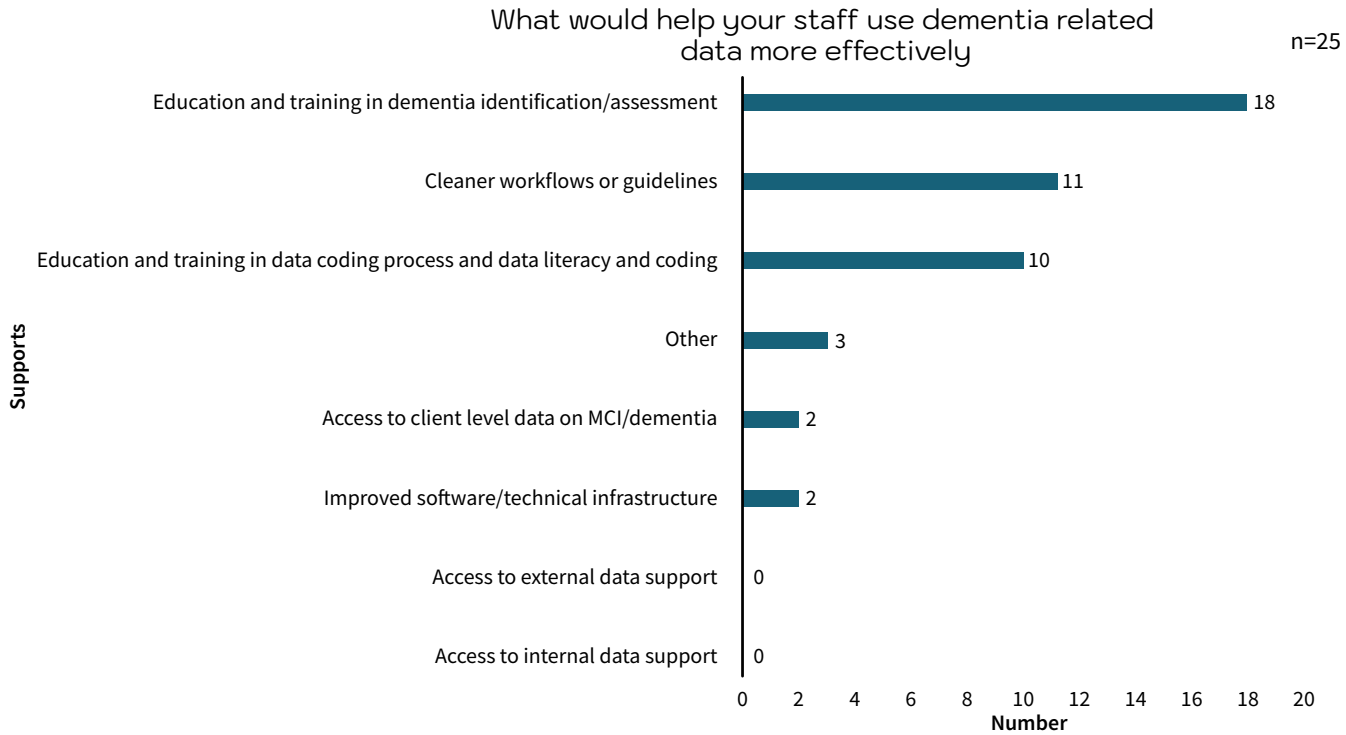


Figure 13. *Respondent report of what would assist staff to use dementia-related data more effectively*

Twenty-five participants responded to a question about what external data uses would be valuable for their health service. A dementia-related nKPI (n=17, 68%) and an Aboriginal and Torres Strait Islander dementia registry (n=14, 56%) were most commonly reported as being valuable for the health service (Figure 14).

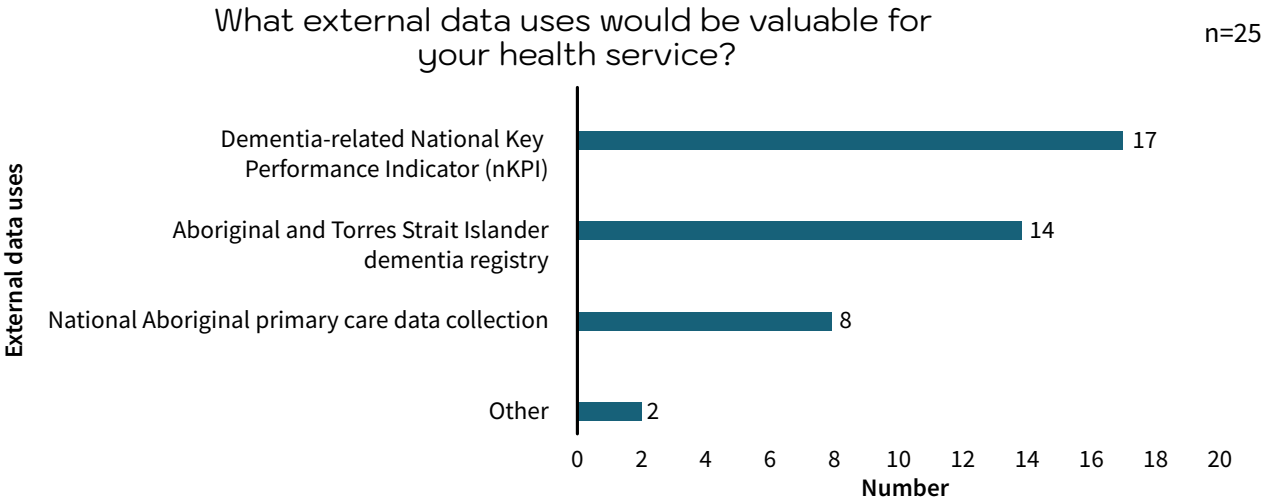


Figure 14. *Respondent report of what external data uses would be valuable for their health service*

Finally, 22 participants responded to a question asking if they would support the development of a co-designed nKPI on dementia. A vast majority (n=20, 91%) of respondents reported that they would support such an initiative (n).

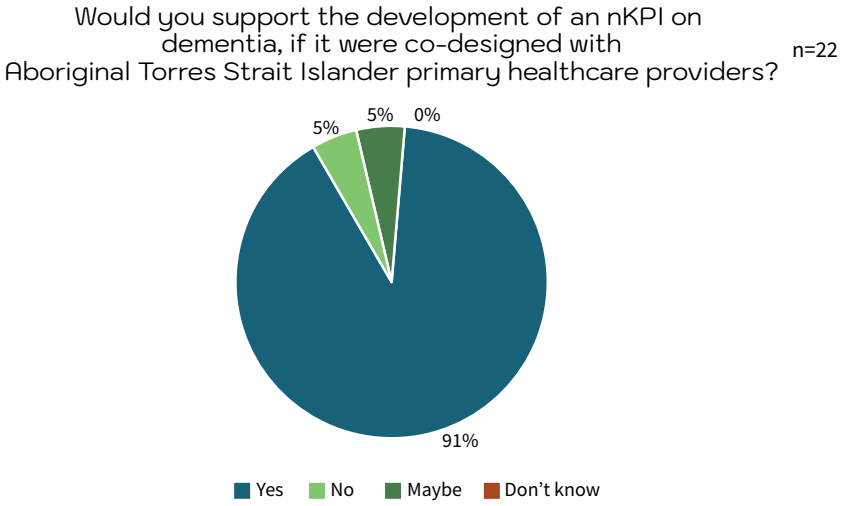


Figure 15*. Respondent report on whether they would support the co-designed development of a nKPI on dementia*

4.4 Project 3 – Expert panel workshop

4.4.1 Participants and demographics

The expert panel workshop, chaired by Prof Sean Taylor, was held **in-person and online** in Naarm-Melbourne in March 2026 and attended by nine participants. We sought expert input from an additional four individual participants who were unavailable to attend the workshop. Of the participants, seven identified as Aboriginal and/or Torres Strait Islander from diverse cultural backgrounds including Alyawarre, Eastern Arrernte, Dauareb (Eastern Torres Strait), Kabi Kabi, Kamilaroi, Wonnarua, Kuku Yalanji, Kulkagal (Torres Strait), Muruwari, Wiriadjuri, Palawa, Panai and Wuthathi. Participants also represented diverse geographies including metropolitan, regional and remote locations across Victoria (Naarm-Melbourne), South Australia (Tarndanya-Adelaide), Queensland (Meanjin-Brisbane, Gimuy-Cairns), Western Australia (Boorloo-Perth, the Kimberley), New South Wales (Banyam-Baigham-Lismore) and the ACT (Ngambri-Canberra) and professional backgrounds including senior researchers, GPs, data governance and sovereignty experts, policy and data advisors and department and NACCHO representatives.

This diversity reflects a wide range of lived experience, professional expertise and cultural knowledges that have guided the development of the final recommendations.

4.4.2 Findings

Workshop findings and final recommendations are presented in Section 5 and Table 2.

5. RECOMMENDATIONS

5.1 Guiding principles

We identified three guiding principles as essential to underpin the implementation of recommendations:

1. **Aboriginal and Torres Strait Islander data governance and data sovereignty**, recognising that ownership, control and governance of data about Aboriginal and Torres Strait Islander peoples rests with Communities.
2. **Codesign and collaboration with APHSs** at all stages of future MCI and dementia data development initiatives.
3. **Strengths-based approaches** must underpin all future MCI and dementia data development initiatives.

These principles are consistent with the ethical and guiding principles in the National Agreement on Closing the Gap Data Development Plan 2022–2030.[45]

5.2 Recommendations

The following section outlines recommendations to improve MCI and dementia data in APHSs across health system, health service, healthcare provider and Community-individual levels (Table 2). While we recognise that many of the recommendations relate to broader health system and service delivery factors, we have presented these alongside more specific data-related recommendations because the quality of data is inextricably linked to the availability and provision of healthcare. Each recommendation includes a brief rationale for its development, the evidence source of informing the recommendation, examples of practical implementation strategies and timeframes for implementation.

Table 2. Recommendations to strengthen MCI and dementia data in Aboriginal and Torres Strait Islander-specific primary healthcare services

Target level of action: Health system				
No.	**Recommendation**	**Rationale**	**Evidence source**	**Timeframe for implementation***

1.	Explore opportunities to strengthen existing, and establish new, Aboriginal and Torres Strait Islander health-specific data governance roles that include oversight of primary healthcare data.
	
	Implementation suggestions:
	• Identify previous and current efforts to establish comparable role(s)
	  ○ Implementation of the Australian Government Framework for Governance of Indigenous Data via the DHDA *Governance of Indigenous Data Implementation Plan*.
	  ○ Expanding the role of the HS-DAG.
	  ○ Implementation of data champions rather than top-down governance.
	• Consider an Aboriginal and Torres Strait Islander-identified data governance Commissioner role as well as technical advisory role(s).
	• Consider a joint role across the DHDA and Aboriginal and Torres Strait Islander peak bodies.
	• Consider scope (including source of data) i.e. whether governance should include all primary healthcare data or only data from APHSs.
		There is a need for oversight of Aboriginal and Torres Strait Islander primary healthcare data to ensure data sovereignty principles are upheld and maintained in all future primary healthcare data collection and use.
		
		This technical role may also have a responsibility to advocate for improved data-related resourcing and facilitating sector education and training on data literacy.
			Qualitative study
			
			Expert panel workshop
				Medium

2.	Develop nationally agreed standards and a guide for two-way data sharing for dementia related data, that can be adapted to local service needs and preferences.
	
	Implementation suggestions:
	• Build on existing data sharing opportunities between AIHW and APHSs
	  ○ Increase visibility of and guidance around accessing publicly available AIHW data e.g. develop guidance-resources to support services to access existing AIHW data.
	  ○ Increase visibility, access to and use of Qlik dashboard (nKPI and OSR data), noting that there are currently no nKPIs or OSR data related to cognition.
	
	• Consider this work within the AIHW National Primary Health Care Data Collection initiative.
		Interest holders consistently expressed a need for data to be returned to them in (more) useful, disaggregated forms so that it can be used internally (by the health service and local community) for QI, service planning, research.
		
		Interest holders who expressed the need for data to be returned to services in useful formats did not provide examples of how this would look, nor did they mention existing two-way data sharing arrangements, such as the Qlik dashboard or other AIHW reports, highlighting the need to increase the visibility of these platforms.
		
		Expert panel members recommended strengthening the capabilities of APHSs to access and interpret existing publicly available AIHW data.
		
		Having access to a guide on data sharing protocols may reduce the burden on services to initiate and develop their own local data release protocols.
		
		Aligns with Closing the Gap Priority Reform Four: Shared access to data and information at a regional level.
			Qualitative study
			
			Expert panel workshop
				Medium

3.	Ensure all APHSs have access to culturally safe and trauma-informed specialist cognition services to support diagnosis and care of Aboriginal and Torres Strait Islander peoples at risk of or living with dementia. ***Implementation suggestions:*** • Integrate visiting geriatricians into APHSs or make sure there is access to external specialist cognition services with locally agreed referral pathways, culturally safe services and timely communication between external specialist services and primary healthcare. • Explore potential models of care to enhance access to memory clinics e.g. hub-and-spoke model. • Ensure that recording of specialist cognition services (consultations) uses standardised dementia data fields and is accessible (discoverable) for monitoring and reporting purposes.	APHS representatives described the limited access to specialist cognition services as a barrier to MCI and dementia diagnosis. Those with access to specialist cognition services described more effective diagnostic pathways for dementia and potential for better data quality. This recommendation aligns with the NDAP Measure 4.3, which aims to track and increase the number of Aboriginal and Torres Strait Islander peoples seen and supported through memory clinics, including through clinics embedded in APHSs.	Qualitative study Survey Expert panel workshop	Long

4.	Develop a measure in the OSR to report on and monitor access to specialist cognition services.
	
	Implementation suggestions:
	• Collect data on services provided by specific medical specialties in the OSR, including specialist cognition (geriatrician) services.
	• Include different models of access in the indicator e.g.
	  ○ Visiting/on-site service
	  ○ Referral to local service
	  ○ Telehealth
		Lack of access to cognition specialist services is consistently identified as a major barrier to dementia diagnosis, and therefore to recording of dementia-related data.
		
		Type of medical specialist accessed is not specified in the OSR (i.e. within the 'episodes of care' indicator).
		
		As stated in the rationale for Recommendation 3, the NDAP aims to track and increase the number of Aboriginal and Torres Strait Islander people seen and supported through memory clinics, including through clinics embedded in APHSs. There are no data currently available to track this measure. The development of an OSR indicator to report on and monitor access to specialist cognition services could support NDAP Measure 4.3.
			Expert panel workshop	Short

5.	Consider adding a cognition or dementia-related service indicator to primary healthcare performance reports; nKPI for Aboriginal and Torres Strait Islander primary healthcare sector and PIPQI measures for mainstream primary healthcare services. ***Implementation suggestions:*** • Indicators for consideration: o Develop a measure that aligns with NDAP Measure 4.3 such as the number of people 50 years and older asked about memory and thinking.	There was some interest holder support for the development of a cognition-related nKPI (if co-designed with services) with a strong preference for a service process rather than outcome measure or measure of dementia prevalence. Interest holders recognised that implementing an nKPI may drive data maturity and that nKPIs are reported externally via an established reporting pathway. Reservations included lack of data maturity and availability from primary healthcare as well as the perennial issue of the burden of data collection in resource constrained environments. Limitations in contributing to prevalence data include nKPIs only being reported by APHSs whilst approximately half of the Aboriginal and Torres Strait Islander population attend mainstream primary healthcare services.	Qualitative study Survey Expert panel workshop	Medium

6.	Promote the AIHW Dementia NBPDS in national conversations about standardisation of CISs data collection and develop an implementation guide for primary care providers. ***Implementation suggestions:*** • Consider developing an implementation guide translating the existing AIHW NBPDS for primary healthcare providers. • Promote to and collaborate with current initiatives i.e. CSIRO-led, FHIR-related work (Australian Clinical Data for Interoperability - Sparked). • Promote inclusion of recommendations on dementia data collection and health record keeping in relevant clinical guidelines e.g. National Dementia Guidelines, National guide to preventive healthcare for Aboriginal and Torres Strait Islander people, CARPA Standard Treatment Manual, Best-practice guide to cognitive impairment and dementia care for Aboriginal and Torres Strait Islander people attending primary healthcare.	There is significant variability between CISs and how these are used by healthcare providers and services. Guidance on data fields and optimal dementia health record keeping could facilitate standardised documentation processes and training to increase availability of discoverable dementia data. AIHW has developed a comprehensive National Dementia Best Practice Data Set that specifies data fields related to cognition and dementia. This could inform translation into a best practice guide for implementation in primary healthcare settings and software development.	Expert panel workshop	Medium
7.	Support workforce capacity in the Aboriginal and Torres Strait Islander-specific primary healthcare sector to address clinical and data needs and preferences. ***Implementation suggestions:*** • Consider additional FTE and support existing initiatives to increase data capacity within services.	Interest holders consistently identified workforce capacity and adequate resourcing as having significant impact on APHSs ability to provide optimal dementia diagnosis and care. Adequate workforce capacity is required to address the complexity of health and social needs, competing priorities in primary healthcare, complexity of dementia, and to improve health record keeping and data use.	Qualitative study Survey Expert panel workshop	Ongoing

8.	Conduct a feasibility study to develop a method that can better estimate Aboriginal and Torres Strait Islander population prevalence of MCI and dementia.
	
	Implementation suggestions:
	• Consider partnership with an Aboriginal and Torres Strait Islander-led research group(s) to lead a feasibility study on monitoring dementia prevalence.
	• Consider estimating prevalence from a representative sample of APHSs.
	• Consider current and future data linkage opportunities including:
	  ○ Primary healthcare and related collections e.g. mainstream general practice data collected by Primary Healthcare Networks, AIHW National Primary Health Care Data Collection.
	  ○ Administrative datasets e.g. ABS, BDM, National Health Data Hub, Person Level Integrated Data Asset.
	  ○ Relevant research and projects e.g. Let's CHAT Dementia, National Primary and Acute Care Data Linkage Project and AIHW's Dementia Data Partnership project with the University of Queensland exploring dementia prevalence.
	• Consider a life-course approach and dementia risk factors in prevalence study.
		Implementing all the changes required in primary healthcare to generate high-quality dementia data is a complex process and long-term goal.
		
		Published academic studies are the only existing and consistent source of dementia data and these are often conducted using small sample sizes or projection modelling.
		
		Considering the complexity of MCI and dementia as health conditions, diagnosis is not always recorded in the primary healthcare environment and is often recorded at the secondary/tertiary care level.
		
		Utilising administrative datasets may improve accuracy of dementia prevalence estimates.
		
		Some jurisdictions have greater data maturity and existing collections that may be linked to existing primary healthcare data collections.
		
		Note, reporting through the OSR and nKPI are not an appropriate mechanism for prevalence estimation.
			Desktop review
			
			Expert panel workshop
				Medium

9.	Strengthen the identification of Aboriginal and Torres Strait Islander peoples in existing administrative collections (e.g. primary healthcare, hospital data, aged care) ***Implementation suggestions:*** • Support availability of existing training programs that strengthen capability of services to appropriately ask about and to accurately document Aboriginal and Torres Strait Islander status including administrative-reception staff and healthcare providers.	Approximately half of Aboriginal and Torres Strait Islander peoples attend non-APHSs. Identified data that can be disaggregated is necessary for an accurate understanding of Aboriginal and Torres Strait Islander specific healthcare needs, and pattern of service use.	Expert panel workshop	Medium

10.	Improve intra- and inter-operability of CISs (within the Aboriginal and Torres Strait Islander-specific primary healthcare sector and between primary healthcare and secondary/tertiary care).
	
	Implementation suggestions:
	• Identify existing work to inform CIS improvements for example:
	  ○ NACCHO Implementation Plan.
	  ○ Sparked CSIRO-led work in developing the Australian Clinical Data for Interoperability.
		Interest holders consistently identified limitations in CISs that acted as barriers to documenting MCI and dementia diagnoses.
		
		Dementia is diagnosed in multiple settings and this needs to be recorded and discoverable across settings. Visibility and discoverability of dementia diagnosis in health records in primary healthcare currently depends on effective communication and transfer of information between providers (e.g. letter from outpatient service, discharge summary from hospital), especially when the diagnosis has been made outside primary healthcare.
			Qualitative study
			
			Survey
			
			Expert panel workshop
				Medium

11.	Ensure ongoing advocacy for dementia as a health priority. ***Implementation suggestions:*** • Promote advocacy for Aboriginal and Torres Strait Islander peoples in existing advocacy organisations and efforts, including consumer and health professional peak bodies. • Ensure dementia is identified and visible as a chronic condition in health data. • Apply a life course approach in promoting brain health and preventing dementia, including raising awareness of dementia risk and protective factors.	Interest holders described that dementia was often not a priority among services due to competing priorities in primary healthcare, and also due to the challenges of pervasive dementia stigma, fear, and ageism. Advocacy is needed at the system level to position dementia as a primary healthcare issue. Historically, dementia has not been considered a chronic condition in health data in the same way as conditions such as diabetes, chronic kidney disease and cardiovascular disease, and some classifications have listed dementia and associated conditions with mental health conditions.	Qualitative study Expert panel workshop	Ongoing

Target level of action: Health services				
No.	**Recommendation**	**Rationale**	**Evidence source**	**Timeframe for implementation***
12.	Implement strategies to increase standardisation of dementia documentation in CISs e.g. use of standardised clinical items in health records (atomic/discoverable data). ***Implementation suggestions:*** • Disseminate national standards and implementation guide on optimal dementia data collection (health record keeping) to APHSs (Recommendation 6).	There is significant variability between CISs and how these are used by healthcare providers. Service data governance decisions should facilitate standardised documentation processes to increase availability of discoverable dementia data.	Desktop review Qualitative study Survey Expert panel workshop	Medium
13.	Include memory and thinking questions in annual health check templates for people over 50 years. ***Implementation suggestions:*** • Include as a recommendation in national standards of optimal dementia data collection for services (Recommendation 6), for implementation by health service managers and senior healthcare providers involved in clinical and data governance.	Memory and thinking questions are not consistently included in the annual health check templates in CISs nor are they consistently asked by healthcare providers in Aboriginal Primary Health Services APHSs. 62% of survey respondents reported consistently asking questions about memory and thinking for Aboriginal and Torres Strait Islander clients over 50 years, while 38% reported inconsistently asking, or not asking at all. Interest holders who participated in qualitative interview-yarns reinforced this lack of consistency. NACCHO–RACGP provides recommended age-appropriate templates for health checks and encourages health services to adapt these to local needs. Health service managers and senior healthcare providers involved in clinical and data governance should make sure memory and thinking questions are enabled in CISs at the service level.	Qualitative study Survey Expert panel workshop	Medium

Target level of action: Healthcare providers				
No.	**Recommendation**	**Rationale**	**Evidence source**	**Timeframe for implementation***
14.	Support availability of ongoing training for healthcare providers working in APHSs to provide ***culturally safe and trauma-informed care*** including: • Primary workforce. • Visiting healthcare providers. • Referred services.	Interest holders consistently identified the critical need for cultural safety and trauma informed practice in how healthcare is available to Aboriginal and Torres Strait Islander peoples.	Qualitative study Survey Expert panel workshop	Ongoing
15.	Support availability of ongoing ***dementia training*** for healthcare providers working in APHSs to build capacity and confidence to recognise signs and symptoms of cognitive impairment, to conduct case finding and culturally safe dementia assessments, and to follow optimal dementia care clinical guidelines. ***Implementation suggestions:*** • Advocate for dementia training in health curricula, including Aboriginal health workers/health practitioners, allied health, Elder Care Support workers, nurses, GPs, other healthcare providers. • Ensure that staff working in APHSs have regular training and capability to complete annual health checks that routinely include asking about memory and thinking. • Include training in use of appropriate cognitive assessment tools.	Interest holders frequently identified the close links between provision of healthcare, health record keeping and data quality, and highlighted a need and preference for both dementia and data training.	Qualitative study Survey Expert panel workshop	Ongoing
16.	Support availability of ongoing training for healthcare providers working in APHSs to build knowledge and skills about ***health record keeping and data literacy***, and to strengthen capabilities of services to use data internally. ***Implementation suggestions:*** • Refer to the NACCHO Digital Health Implementation Plan. • Increase visibility and enable access to tools that enable internal data use e.g. clinical audit, Qlik dashboard.	There is significant variability between CISs and how these are used by healthcare providers, especially those working across diverse settings (transient workforce). Ability to work across different CISs and conduct accurate health record keeping is required to increase availability of accurate and discoverable dementia data. Many services do not have the workforce capacity to collect or use data internally either through a lack of dedicated data or informatics staff, skills and knowledge gaps or competing priorities.	Desktop review Qualitative study Survey Expert panel workshop	Ongoing

Target level of action: Community-Individuals				
No.	**Recommendation**	**Rationale**	**Evidence source**	**Timeframe for implementation***
17.	Identify opportunities for health promotion and Community education about dementia, based on a life course approach, including • Brain health. • Risk and protective factors. • Dementia diagnosis. • Healthcare and supports for people living with dementia and their carers, families and communities. ***Implementation suggestions:*** • Identify and develop culturally appropriate dementia literacy and health promotion initiatives and resources.	Interest holders frequently described that Community shame, stigma and fear surrounding dementia, and lack of culturally appropriate services create barriers to people presenting to primary healthcare. A higher level of dementia literacy encourages community members to engage with primary healthcare providers about memory and thinking which in turn can improve diagnosis and documentation of MCI and dementia. Health promotion and Community education is an intrinsic and ongoing part of the role of primary healthcare.	Qualitative study Expert panel workshop	Medium

APHS, Aboriginal and Torres Strait Islander-specific primary healthcare services; CISs, clinical information systems; HS DAG, Aboriginal and Torres Strait Islander Health Services Data Advisory Group; NBPDS, National Best Practice Data Set; nKPI national Key Performance Indicator; OSR, Online Services Report; PIPQI, Practice Incentive Program Quality Improvement; MCI, mild cognitive impairment

*Suggested implementation timeframe based on impression of feasibility, system readiness and complexity of action. Development of a formal implementation plan is required. Short term, within 1 year; medium term, 1 to 3 years; long term, 3 years and longer. Many of the recommendations require initial and ongoing implementation. In this case, the ongoing timeframe is not included. Some are only meaningful as having an ongoing timeframe for implementation.

6. CONCLUSION

This report responds to the AIHW's request for evidence and recommendations with rationales on strengthening MCI and dementia data with and for Aboriginal and Torres Strait Islander peoples who attend APHSs. Drawing on evidence gathered through a desktop review, qualitative key informant interview-yarns with dementia data interest holders, a national cross-sectional survey and an expert panel workshop, we have described the current APHS dementia data environment, key data and health service gaps, barriers and enablers to systematic data collection in APHSs, and the dementia data needs and preferences of APHS interest holders. Drawing on this evidence, we propose 17 recommendations to strengthen MCI and dementia data for Aboriginal and Torres Strait Islander peoples. The recommendations include suggested actions at the health system, health service, healthcare provider and Community-individual level and suggest a timeframe for completion. Implementation of these recommendations should be underpinned by principles of Aboriginal and Torres Strait Islander data governance and data sovereignty, co-design and collaboration, and strengths-based approaches.

Although some key questions have been addressed, many remain or have been made more visible by this project. Our findings reinforce what is known about the substantial MCI and dementia data gaps identified in previous dementia data policies.[20] They also demonstrate that data quality in APHSs is directly impacted by gaps in healthcare service delivery, specifically services' and healthcare providers' capacity to detect and document MCI and dementia. The first step in the primary healthcare data journey is a client engaging with a health service[18] and a provider recording clinical information in a health record. Limited access to culturally safe specialist cognition services, competing priorities in primary healthcare, a constrained workforce, variable clinical capabilities and dementia-related stigma and fatalism all impact Aboriginal and Torres Strait Islander peoples' access to culturally safe dementia care. These challenges have significant impacts on what data is currently recorded in APHSs and therefore what can be routinely accessed or reported.

Future MCI and dementia data development initiatives must include strategies to increase access to culturally safe dementia care for Aboriginal and Torres Strait Islander peoples at risk of or living with MCI or dementia. Previous work by members of the project team, such as the Let's CHAT Dementia project,[46] demonstrates that effective culturally safe models of dementia care have been developed, and those that increase availability of and access to specialist cognition services have the potential to improve dementia diagnoses. Addressing this gap in care is critical to optimising the health and wellbeing of Aboriginal and Torres Strait Islander peoples living with or at risk of dementia, and their carers, families and communities. Importantly, service gaps and data gaps must be addressed simultaneously and within the context of broader work (including the development of the NPHCDC, current OSR and nKPI reviews, and other AIHW primary healthcare data development) rather than sequentially. Improvements in dementia data collection cannot wait for improvements in dementia detection, diagnosis and care, because data both reflects current practice and provides the evidence needed to drive and monitor service improvement. Sustained improvement in data collection and use, informed by agreed standards, should therefore proceed in parallel with efforts to strengthen culturally safe dementia care.

Our findings and recommendations reinforce some of the outcomes of previous reports and align with existing work in progress in some areas of MCI and dementia data collection and development. This includes previous efforts to appoint Aboriginal and Torres Strait Islander data governance roles, NACCHO-led data improvement initiatives, exploring established models for routine data collection and reporting in other clinical domains, and improving the identification of Aboriginal and Torres Strait Islander peoples in existing data collections. Data maturity in APHSs needs to be strengthened to improve data quality, that would in turn create opportunities for data linkage to additional MCI and dementia data sources.

Limitations and opportunities for future research and development

This project has some limitations to consider. It was established to focus solely on the APHS sector and therefore represents only part of the population, noting that approximately half of Aboriginal and Torres Strait Islander peoples attend mainstream primary healthcare services. Future research will need to consider which recommendations are applicable to mainstream primary healthcare and related sectors, including aged care, to ensure a a more complete picture of Aboriginal and Torres strait islander MCI and dementia prevalence. It should consider how lessons from APHSs, mainstream primary healthcare services and national primary healthcare data development initiatives can inform one another. Another limitation of this project was the challenge in differentiating between MCI and dementia data collection; however, the implications and opportunities for future work in improving dementia data are likely to be applicable to MCI data.

Our cross-sectional survey results had a relatively small number of respondents, which hindered our ability to perform more complex statistical analyses (e.g. to report survey findings by service type or geographical location). Although the number of respondents was small, the response rate was relatively high for this group, responses were distributed across Australia and service types, and survey findings closely aligned with those from the qualitative study, suggesting that a larger sample may not have yielded substantially different insights.

Lastly, future work will need to account for clinical and technological advances that have the potential to rapidly change the dementia diagnosis and care landscape. In particular, the emergence of blood-based biomarkers for dementia, particularly Alzheimer's disease (the most common form of dementia), and the development of minimally invasive, diagnostic technologies may have a significant impact on diagnostic processes in primary healthcare. The impact of artificial intelligence (AI) is unknown and will require careful evaluation. The increasing uptake of AI tools, such as AI scribes used by many healthcare providers, may compound existing challenges, as these tools typically input clinical information into free text fields, rather than structured or coded fields, and therefore limiting the amount of extractable dementia data available in CISs. Alternatively, the use of AI may help resolve structural issues such as workforce capacity by freeing clinician time or improving data extraction and analysis tools.

Next steps

The recommendations developed through this project lay an important foundation for ongoing, Aboriginal and Torres Strait Islander-led work to strengthen MCI and dementia data in APHSs. A key next step will be to develop, in partnership with NACCHO and state and territory Aboriginal and Torres Strait Islander peak bodies, a detailed implementation plan for each recommendation. Acting on the recommendations will ensure that data development and practices contribute meaningfully to better dementia care and outcomes for Aboriginal and Torres Strait Islander peoples across the life course.

GLOSSARY

Aboriginal and Torres Strait Islander peoples: Aboriginal and Torres Strait Islander peoples and communities across Australia comprise many distinct Nations, clans and language groups, each with diverse histories, cultural traditions, languages, and systems of law and lore. These communities maintain deep and enduring connections to Country, Community, culture, and kinship systems.

Aboriginal Community Controlled Health Organisation (ACCHO): A primary healthcare service run by the local Aboriginal community to provide culturally safe healthcare for Aboriginal and Torres Strait Islander peoples. Most ACCHOs receive funding from the Australian Government through the Indigenous Australians' Health Programme.

Aboriginal and Torres Strait Islander-specific primary healthcare services (APHS): Primary healthcare services with a range of governance and funding arrangements that provide culturally safe healthcare for Aboriginal and Torres Strait Islander peoples.

Administrative data: Data collected by government departments, businesses and other organisations as part of their delivery of services or conducting their business, that can include operational, financial, clinical, and patient/client management data. While the data are primarily collected for non-statistical purposes, the 'secondary use' of the data can provide a rich source of information about health and wellbeing and information about how people interact with health and other community services.

Co-design: A collaborative process where community members, researchers and partners work together to design research, resources, policies or solutions that reflect everyone's needs and priorities.

Community: Describes relationships including cultural, emotional and social ties that exist between Aboriginal and Torres Strait Islander peoples, families, kin and Country. Community is capitalised to reflect the meaning Community holds in an Aboriginal and Torres Strait Islander cultural context.

Cultural safety: Involves people and organisations addressing systemic barriers in order to provide culturally appropriate and responsive research and healthcare environments. It is an approach to research and healthcare that requires ongoing reflection on cultural assumptions and behaviours, to ensure that cultural values, practices, knowledge systems and ways of being are respected and that Aboriginal and Torres Strait Islander peoples' feel safe and respected in cultural identity.

Data: The information collected during research and clinical consultations. It may be expressed in numbers (quantitative data), pictures (such as x-rays, drawings or photos) or in words (descriptions of experiences and stories).

Data governance: Oversight and decision-making practice that enables the enaction of data sovereignty principles. It ensures that data on or about Aboriginal and Torres Strait Islander peoples have the right to autonomously decide what, how and why Aboriginal and Torres Strait Islander data are collected, accessed and used and that data reflects Aboriginal and Torres Strait Islander people priorities, values, cultures, worldviews and diversity.

Data use: Any process of coding, analysing, interpreting and applying collected data to gain insights or make informed decisions. Data use can involve activities such as quality improvement, research, planning, evaluation, monitoring, reporting or service development.

Data sovereignty: The right of Aboriginal and Torres Strait Islander peoples to control how data and knowledge about individuals and communities is collected, stored, used, and shared.

Dementia: A group of conditions characterised by progressive decline in memory, thinking and/or behaviours that affects a person's ability to perform everyday activities. There are many types of dementia, including dementia due to Alzheimer disease (the most common type), dementia due to Lewy Body Disease, vascular dementia, and frontotemporal dementia.

Elder: An Aboriginal and/or Torres Strait Islander Elder is someone who is highly respected and recognised in their Community as a custodian of cultural knowledge.

Grey literature: Information or evidence that is produced on all levels of government, academics, business and industry, but which is not controlled by commercial publishers. Common grey literature resources include government reports, policy documents, technical reports, practice guidelines and conference proceedings.

Hub-and-spoke model: A model that comprises a central point (hub) with a full array of services that is linked to secondary settings (spokes or satellites) that have limited services and can refer in to the central hub

Indigenous Australians Health Programme (IAHP): an Australian Government funding stream that funds Aboriginal and Torres Strait Islander-led, culturally appropriate initiatives to increase access to health care and improve the health of Aboriginal and Torres Strait Islander peoples, including but not limited to ACCHOs.

Interest holder: An individual or group with legitimate interest in a health issue or topic under consideration.

Life-course approach: In the context of dementia, a life-course approach recognises that optimising brain health and prevention of age-related diseases depends on addressing many modifiable strengthening and risk factors at each stage of life.

Mild cognitive impairment (MCI): A brain condition that involves subtle changes to memory and thinking that are not a normal part of healthy ageing and may increase an individual's risk of developing dementia.

National Key Performance Indicator (nKPI): Reported by organisations receiving funding under the Australian Government's Indigenous Australians' Health Programme to deliver comprehensive and culturally safe primary healthcare services to Aboriginal and Torres Strait Islander peoples. The nKPIs are both process and outcome indicators that focus on maternal and child health, preventive health and chronic disease management to evaluate progress towards achieving the goals of the National Aboriginal and Torres Strait Islander Health Plan and Closing the Gap health outcomes.

Online Services Report (OSR): Reported by organisations receiving funding under the Australian Government's Indigenous Australians' Health Programme to deliver comprehensive and culturally safe primary healthcare services to Aboriginal and Torres Strait Islander peoples. The OSR collects and contains context information about each organisations as well as aggregate counts of number of clients, episodes of care and staffing FTEs.

OnTRACK (Teaching, Research and Community Knowledges) Centre of Research Excellence: A specific research program that promotes brain health and supports culturally safe dementia research and care with Aboriginal and Torres Strait Islander peoples and communities.

Quality improvement (QI) or continuous quality improvement (CQI): Systems of regularly reviewing and refining processes to improve them, for example to improve how healthcare is delivered.

Primary healthcare: Healthcare people seek first in their community, for example general practitioners (GPs), pharmacists, allied health or Aboriginal and Torres Strait Islander-specific healthcare services. Primary healthcare represents the frontline and/or entry level to the health system.

Reporting: The process of collecting, analysing, organising and presenting data to easily understandable formats to inform and monitor performance.

Sovereignty: The right of Aboriginal and Torres Strait Islander peoples to make our/their own decisions about research involving our/their people, data, and knowledge.

ABBREVIATIONS

ABS: Australian Bureau of Statistics

ACCHO: Aboriginal Community Controlled Health Organisation

AIHW: Australian Institute of Health and Welfare

AMS: Aboriginal Medical Service

APHS: Aboriginal and Torres Strait Islander-specific primary healthcare service

AUCDI: Australian Clinical Data for Interoperability

CIS: Clinical information system

CSIRO: Commonwealth Scientific and Industrial Research Organisation

DGG: Data Governance Group

GP: General practitioner

IAHP: Indigenous Australians Health Programme

MCI: Mild cognitive impairment

NACCHO: National Aboriginal Community Controlled Health Organisation

NBPDS: National Best Practice Data Set

NDAP: National Dementia Action Plan

NDDIP: National Dementia Data Improvement Plan

nKPI: national Key Performance Indicator

NPHCDC: National Primary Health Care Data Collection

OnTRACK CRE: OnTRACK (Teaching, Research and Community Knowledges) Centre of Research Excellence

OSR: Online Services Report

PIPQI: Practice Incentives Program Quality Improvement

QI: Quality improvement

RACGP: Royal Australian College of General Practitioners

RWG: Research Working Group

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APPENDICES

Appendix 1. Detailed methodology and methods

Phase 1: Desktop review

Objectives

- To identify the current mild cognitive impairment (MCI) and dementia data environments within Aboriginal and Torres Strait Islander-specific health services (APHSs) i.e. administrative datasets, current data holdings, or datasets with the potential to include MCI or dementia data for Aboriginal and Torres Strait Islander peoples
    - To explore and describe each dataset identified, including information on:
    - The data holders/owners of each dataset
    - How the data was collected and coded
    - Who currently accesses and/or uses each dataset and;
    - Any limitations (legal or cultural) placed on the use of the data.

Process

We performed a desktop review using a modified, grey literature[8] search and scientific database search to identify in-scope data collections that included: i) MCI and dementia diagnoses ii) Aboriginal and/or Torres Strait Islander status and iii) access to or utilisation of APHSs.

Search strategy and source identification

Online searches were undertaken in consultation with a medical librarian (information specialists that manage and organise health information and research resources who have specialised knowledge in designing systematic search strategies to identify biomedical literature) using an advanced Google search, searches of relevant government websites (e.g. Australian Institute of Health and Welfare [AIHW], Australian Bureau of Statistics [ABS]) and an academic database search including Scopus, Web of Science and the Australian Indigenous Health Infonet. Key search terms across both searches included "Aboriginal" OR "Torres Strait Islander" OR "First Nations" OR "Indigenous" AND "dementia" OR "cognitive impairment" to identify in-scope data collections. We did not include the healthcare setting in search terms or limit results by research methodology as this resulted in too few resources being retrieved.

The results were screened to identify any in-scope resources that included Aboriginal and Torres Strait Islander people who had a diagnosis of MCI or dementia. For resources that met our inclusion criteria, full-text resources were read to identify: i) the primary source of data i.e. whether the study was reporting new data, and ii) how the data were collected, or iii) whether the study was using secondary or previously reported data.

Citation searching of resources reporting an analysis of secondary or previously reported data was performed to identify sources of primary MCI and dementia. We also consulted with subject-matter experts including members of the Data Governance Group (DGG), Research Working Group (RWG) and representatives from AIHW to identify any additional relevant studies or resources that may not have been identified during our initial searches.

Phase 2a: Qualitative key informant study – Interviews with ASHSs service providers

Objectives

- To explore current data collection practices i.e. recording clinical information among APHS healthcare providers in relation to MCI and dementia.
- To explore barriers and enablers to MCI and dementia/ data collection and use among APHS healthcare providers

To explore APHS healthcare providers' data needs and preferences in relation to Aboriginal and Torres Strait Islander peoples with MCI or dementia accessing their services

Study design

We conducted a qualitative key informant study. A key informant study collects information from participants who are considered community experts; invaluable, expert sources of information who, as a result of their expertise or position within a community or organisation can provide insider information about a concept, group, culture, or subject.[9] The key informant approach enabled us to explore data-related questions with a diverse range of Aboriginal and Torres Strait Islander primary healthcare and dementia data interest holders.

Participants and recruitment

Eligible participants were health providers, managers and data and informatics staff from a diverse range of APHSs across metropolitan, regional and remote locations nationally. We also sought representation from key government and non-government agencies involved in dementia and primary healthcare data and research. Initially, participants were purposively sampled (Palinkas et al 2015) by drawing on the project team's professional networks that have been established through past and current clinical and research work. Purposive sampling was augmented by snowball sampling (Valerio et al 2016), where enrolled participants recommended additional key informants who met the eligibility criteria. Snowball sampling resulted in several dyad interviews and two yarning circles. Participants were offered reimbursement for their time in the form of a $100 Visa gift card. Recruitment, data collection and data analysis were conducted in parallel, and recruitment ceased when informational power[47] was reached (i.e. the point at which sufficient data was obtained to observe patterns in meaning between participants that could answer the research question).

Data collection

- Data were collected through one-on-one, dyad interviews and yarning circles conducted between June and October 2025.[26] Research yarning was used where appropriate (i.e. when Aboriginal and Torres Strait Islander community members were present).[26] A semi-structured interview schedule (Appendix 2) was used to guide data collection and elicit participants' knowledge and experiences in relation to:
- Dementia diagnoses.
- Health record keeping.
- Barriers and enablers to data collection, availability and quality of data on MCI and dementia diagnoses.
- Data needs and opportunities to improve the quality of data available in relation to Aboriginal and Torres Strait Islander peoples living with MCI or dementia.

All interviews and yarning circles were audio recorded and transcribed by a local external transcription service that follows Commonwealth privacy laws. Interviews and yarning circles were conducted by one or a combination of three researchers: the lead investigator, qualitative researcher, social scientist and woman with a background in public and Aboriginal and Torres Strait Islander health; a GP, research consultant and woman with extensive experience in Aboriginal and Torres Strait Islander-specific primary healthcare and; a Worimi man and research assistant with experience in Indigenous studies and culturally secure research methods.

Data analysis

Transcribed interview data were analysed using both content analysis[28] and inductive reflexive thematic analysis.[29] Content analysis was used as a tool for identifying common issues and topics to be included in the design and development of the survey in Phase 2b. Reflexive thematic analysis was also used to acknowledge that the researchers played an active role in the construction of meaning of the participants' descriptions via contributing their expertise as healthcare providers and researchers with backgrounds in geriatric medicine, primary healthcare, public health and a common interest in optimising the health and wellbeing of Aboriginal and Torres Strait islander peoples at risk of or living with dementia, their carers, families and communities.

The lead researcher reviewed and conducted initial coding of the transcripts to generate a preliminary coding framework. The coding framework was presented to the multidisciplinary project team, including researchers involved in data collection, to ensure that the provisional codebook covered all relevant concepts. A second researcher (a Worimi Researcher) (tested the refined framework on four transcripts to verify it was complete and to provide cultural oversight of the analysis. Coded data were organised into themes and presented to the multidisciplinary project team, the DGG and RWG where they were discussed, refined and challenged in the context of existing theory and clinical practice.

Phase 2b: Cross-sectional survey

Objectives

- To explore current data collection practices i.e. recording clinical information among healthcare providers providing MCI and dementia care to Aboriginal and Torres Strait Islander clients.
- To explore barriers and enablers to MCI and dementia data collection and use among APHS healthcare providers.
- To explore APHS healthcare providers' data needs and preferences in relation to Aboriginal and Torres Strait Islander peoples living with MCI or dementia accessing their services.

Study design

We conducted a national, online cross-sectional survey of APHS staff from February to March 2026. The main themes identified from the interviews and yarning groups (Phase 2a) informed the development of survey sections and items. Survey items were organised into four main sections: i) Role and healthcare setting, ii) Current cognitive assessment and diagnostic practices, iii) Existing data collections and internal data uses, and iv) Data needs, preferences and opportunities. RWG members provided input into preliminary survey questions, which were then piloted with two APHS staff members (a geriatrician and an Aboriginal Health Worker) who suggested minor wording changes.

Data collection

The survey was administered using Qualtrics software and completed by respondents anonymously online. The intended respondents were managers, senior healthcare providers and data/informatics staff working in APHSs and our participant inclusion criteria were stipulated in the survey preamble. Multiple respondents per service were permitted where appropriate, to explore diverse perspectives on dementia data in APHSs. The survey was promoted via an email invitation that was distributed to a custom mailing list developed by the project team by collating publicly available APHS and representative staff emails from the National Aboriginal Community Controlled Health Organisation (NACCHO) service list and a list of IAHP-funded services that report to the OSR provided by DHDA. An email invitation containing the survey link and study information was distributed to 264 identified contacts from 155 unique APHSs. This approach was combined with snowball sampling, whereby email recipients were encouraged to invite other appropriate APHS staff to participate. Survey study information outlined the purpose of the study, the voluntary nature of participation, the intended respondent group (service managers, senior healthcare providers and data/informatics staff), and the approximate time required to complete the survey (10–12 minutes). Proceeding past the preamble was taken as implied consent. Weekly email reminders were sent to the survey contact list over the four-week period that the survey was open. In the spirit of reciprocity, survey respondents were provided with links to resources on best-practice cognitive impairment and dementia care for Aboriginal and Torres Strait Islander peoples attending primary healthcare.

Data analysis

Respondent surveys in which demographic data and at least one service-based question was completed were included in the analysis. Data were analysed using descriptive statistics. Aggregated results are presented using frequency (percentage) tables, pie charts and histograms.

Phase 3: Expert panel workshop

Objectives

- To integrate and interpret findings from Projects 1, 2a and 2b.

To refine a set of recommendations for improving the availability and quality of MCI and dementia data among Aboriginal and Torres Strait Islander peoples to present to the AIHW.

Study design

Findings from Phase 1, 2a and 2b were integrated and interpreted by the project team to inform the development of a draft set of recommendations to improve MCI and dementia data in APHS (the recommendations).

Participants and process

We convened a full-day workshop to seek expert input into, and refine the draft recommendations. Workshop participants were identified and invited through the professional networks of the project team, DGG, RWG and AIHW NCMD, and included a diverse expert panel from across Australia, comprising:

- Aboriginal and Torres Strait Islander researchers and healthcare providers.
- Health service staff from APHS including GPs, geriatricians.
- Academic and policy experts with expertise in data, data governance and data sovereignty.
- Government and governance leaders including representatives from Aboriginal and Torres Strait Islander health services peak bodies.

Following a presentation of project findings, a group discussion was co-facilitated by PO and MB to solicit feedback on the draft recommendations. Discussion of each recommendation was guided by the same questions:

1. Is the recommendation clear?
2. Does the recommendation align with the evidence we have presented?
3. Does the recommendation fit within your knowledge or expertise? Anything to change or add?
4. Suggestions for implementation?

Workshop participants were also encouraged to focus on what is practical and practicable, so that strategies for implementation could be suggested alongside each of the recommendations. Data generated in the workshops comprised in-depth researcher notes and memos documenting the content of discussions. Researcher notes and memos were analysed using a framework analysis, where workshop data were coded into a matrix using the draft recommendations as pre-defined categories, whilst also allowing additional insights or new recommendations to be identified.[30]

Appendix 2. Example semi-structured interview/yarning guide

Section & Purpose	Example Question / Prompts
Social Yarn Build rapport and trust, create a culturally safe space	• How's your day been so far? • What's keeping you busy at the moment — in work or otherwise? • Tell me a bit about yourself? Age, Country/language group, place of residence, occupation, hobbies? • Can you tell me a little about where you're based and the community you work with? • Can you tell me a bit about your family? • What is a favourite place you have lived, worked or travelled to?
Introduction and Context Setting Introduce project and process, confirm consent	• Acknowledgement of Country • Provide brief overview of the project and interview purpose • Confirm that you are putting on the recorder • Reconfirm voluntary consent 'on the record' • What interested you in participating? • Tell me about your occupation/position, time in position etc
Current Practices in MCI/ and Dementia Data Collection Understand how data is currently collected, stored, and used	• How does your service currently identify and record information about clients with cognitive impairment/dementia? • Is there a standardised approach? • How does this differ from data that is collected about other chronic conditions (e.g. diabetes) • Who is involved in diagnosis or assessment of MCI or dementia? • What systems or tools (e.g., clinical software) does your service use for this information? • How are referrals recorded?

Barriers and Enablers to Data Collection and Use
 	
Explore challenges and supports in current systems
	• What helps your service collect good-quality information about dementia?
	• What are the barriers or challenges to recording dementia diagnoses/ data at your service?
	  ○ Technical/software
	  ○ Resources
	  ○ Staff
	  ○ Cultural
	• Is this data used internally once collected (e.g. care planning, reporting, research)?
	  ○ If yes, how?
	• Is this data used externally once collected (e.g. care planning, reporting, research, funding)?
	  ○ If yes, how?

Data Needs and Preferences
 	
Identify opportunities and ideal conditions for improvement
	• What do you think would improve or support dementia data collection?
	  ○ Software changes?
	  ○ SOPs/systemic changes
	  ○ Personnel?
	• Are there any changes you'd like to see in your current systems?
	• What would a culturally safe and useful data system look like to you?

Broader Reflections and Recommendations Gather insight for systems-level changes and project recommendations	• What would help strengthen dementia data collection nationally across ACCHOs/AMSs? • How do you think improvements in data on dementia might help ACCHOS/AMSs care for their clients? • Are there any key messages or recommendations you'd like to share us / AIHW?
Wrap up and interview/yarn close	• Is there anything else you'd like to share? • Anyone else you think would be important for us to talk to? • Would you like to stay in touch for the next stages of the project (survey?)

Appendix 3. Survey instrument

DEMENTIA DATA DEVELOPMENT SURVEY

Start of Block: Introduction

This survey is intended for service managers, senior clinicians and data/informatics staff working in Aboriginal and Torres Strait Islander–specific primary healthcare services. We are seeking your help to improve the service system for Aboriginal and Torres Strait Islander people **at risk of, or living with, dementia**. High-quality data are essential for planning and health care delivery; however, there are recognised gaps in dementia-related data. This project, commissioned by the Australian Institute of Health and Welfare (AIHW) and led by the University of Melbourne, aims to better understand these gaps and develop recommendations to strengthen dementia and mild cognitive impairment (MCI) data in Aboriginal and Torres Strait Islander–specific primary healthcare. The aims of this survey are to: • Describe current dementia and MCI assessment, diagnosis and data documentation practices • Identify opportunities to strengthen dementia and MCI data collections in Aboriginal and Torres Strait Islander–specific primary healthcare • Understand service-level data needs related to dementia and MCI The survey was informed by the findings of a qualitative study with representatives from the Aboriginal and Torres Strait Islander primary healthcare and community-controlled sector, and with input from an Aboriginal and Torres Strait Islander Data Governance group. Survey responses will help refine earlier findings and inform recommendations to AIHW. Participating in the survey is voluntary. Reporting of the results of this survey will be aggregated so that no individual or service can be identified. The survey will take approximately 10-12 minutes. We thank you for sharing your time and expertise. ***Ethical approval for this project was obtained from the University of Melbourne Human Research Ethics Committee (Project ID 32352) the Aboriginal Health and Medical Research Council Ethics Committee (2437/25), the Western Australian Aboriginal Health Ethics Committee (HREC1433) and the Australian Institute of Aboriginal and Torres Strait Islander Studies Research Ethics Committee (REC-0584).***

SECTION 1: ROLE AND HEALTHCARE SETTING

1.1 What is your current role?

_____

1.2 How long have you been in this position? (years and/or months)

_____

1.3 Do you identify as Aboriginal and/or Torres Strait Islander?

- ○ Aboriginal (1)
- ○ Torres Strait Islander (2)
- ○ Aboriginal and Torres Strait Islander (3)
- ○ Non-Indigenous (4)

1.4 What is your health service/organisation's funding source?

- ○ Indigenous Australian Health Program (IAHP)-funded only (1)
- ○ State/Territory Government-funded only (2)
- ○ Combined IAHP and State/Territory-funded (3)
- ○ Other (please specify) (4) _____
- ○ Unsure (5)

1.5 What is the postcode of your service's primary location?

_____

1.5.1 How would you describe the location of your service?

- ☐ Metropolitan (1)
- ☐ Inner regional (2)
- ☐ Outer regional (3)
- ☐ Remote (4)
- ☐ Very remote (5)
- ☐ Unsure (6)

1.6 Estimated total number of Aboriginal and/or Torres Strait Islander regular clients attending your service per year

_____

1.7 Estimated number of Aboriginal and/or Torres Strait Islander regular clients over 50 years attending your service per year

_____

1.8 Which clinical software system(s) does your service use?

- ○ Best Practice (1)
- ○ Communicare (2)
- ○ Medical Director (3)
- ○ MMEX (4)
- ○ Other (please specify) (5) _____

SECTION 2: CURRENT COGNITIVE ASSESSMENT AND DIAGNOSTIC PRACTICES

2.1 Does your service routinely ask questions about memory and thinking as part of annual health checks (MBS 715) for Aboriginal and/or Torres Strait Islander clients 50 years and over?

- ○ Yes, consistently (1)
- ○ Yes, but inconsistently (2)
- ○ No (3)
- ○ Unsure (4)

2.2 Does your service currently use any cognitive assessment tools?

- ○ Yes, consistently (1)
- ○ Yes, but inconsistently (2)
- ○ No (3)
- ○ Unsure (4)
- ○ Other (please comment) (5) _____

2.2.1 Please indicate which cognitive assessment tools are used in your service (select all that apply)

- ☐ KICA/KICA-Cog (Kimberley Indigenous Cognitive Assessment (1)
- ☐ MMSE (Mini-mental State Examination (2)
- ☐ MoCA (Montreal Cognitive Assessment (3)
- ☐ RUDAS (Rowland Universal Dementia Assessment Scale) (4)
- ☐ Other (please specify) (5) _____

2.3 What are the most important barriers to diagnosing dementia at your service?
Please drag and drop up to five barriers into the box, then prioritise by ranking 1-5 (1= most important)

5 most important barriers

_____ None - there are no barriers
_____ Limited time available during appointments
_____ Limitations in staff knowledge/skills
_____ Transient workforce
_____ Complex social and health circumstances of clients
_____ Competing priorities in primary healthcare
_____ Lack of standardised referral pathways
_____ Lack of standardised assessment processes
_____ No definitive diagnostic test
_____ Difficulty accessing specialist cognition services
_____ Community stigma about dementia
_____ Clinician discomfort raising cognitive impairment with clients
_____ Clinician perceived lack of value in diagnosis
_____ Other (please specify)

2.3.1 Please provide any further comment on barriers to diagnosing dementia in your service

_____

2.4 Are there any processes or approaches to diagnosing dementia and/or MCI that work well at your service?

- ○ Yes (please describe) (1) _____
- ○ No (2)
- ○ Don't know (3)

SECTION 3: EXISTING DATA COLLECTIONS AND INTERNAL DATA USES

3.1 Does your service routinely record dementia and/or MCI diagnoses in the clinical software?

- ○ Yes, consistently using clinical/coded items only (1)
- ○ Yes, consistently using free text only (2)
- ○ Yes, consistently using both coded and free text options (3)
- ○ Yes, but inconsistently (4)
- ○ No, we don't record in clinical software (5)
- ○ Don't know (6)

3.2 Is dementia-related data used internally at your service for purposes other than direct client care? (select all that apply)

- ☐ Internal auditing (e.g. of cognitive assessments performed, number of dementia diagnoses) (1)
- ☐ Internal reporting within the service or between related services (2)
- ☐ Continuous quality improvement/QI (3)
- ☐ Program or service planning (4)
- ☐ Workforce planning (5)
- ☐ Research (6)
- ☐ To apply for funding (7)
- ☐ No current use of dementia related data for anything other than direct client care (8)
- ☐ Other (please specify) (9) _____

3.3 What challenges does your service face when using dementia-related data?
Please drag and drop up to five challenges into the box, then prioritise by ranking 1-5 (1= most important)

5 most important challenges

_____ Dementia underdiagnosed (1)

_____ Poor data quality (e.g. missing data, incorrect data) (2)

_____ Inconsistent documentation and coding processes (3)

_____ Difficulty tracking diagnoses across services (4)

_____ Lack of time to code data (5)

_____ No dedicated staffing for data management (6)

_____ Lack of access to data teams or external support (7)

_____ Limited data literacy among staff (8)

_____ Limitations in software design (e.g., no fields, difficult workflows, lack of interoperability) (please describe) (9)

_____ Perceived lack of value in collecting or using dementia data (10)

_____ Other (please specify) (11)

_____ None (12)

3.3.1 Please provide any further comment on challenges to using dementia-related data in your service

_____

SECTION 4: DATA NEEDS, PREFERENCES AND OPPORTUNITIES

4.1 What would be most helpful to support diagnosis of dementia at your service? ***Please drag and drop up to five supports into the box, then prioritise by ranking 1-5 (1= most important)***

5 most important supports

_____ Staff education and training about dementia (1)

_____ Community education about dementia (2)

_____ More frequent administration of the annual health checks (MBS 715) for clients 50 years (3)

_____ Standardised cognitive assessment tools (4)

_____ Streamlined documentation processes in software (5)

_____ Better communication between healthcare providers (primary healthcare and other) (6)

_____ Agreement on what clinical items/codes to use for dementia (7)

_____ Longer consultations with clients in primary healthcare (8)

_____ Improved continuity of care (i.e. clients more often seeing clinician(s) on an ongoing basis) (9)

_____ Staff education and training about competing priorities in consultations (10)

_____ Collaborative, multidisciplinary and interprofessional approaches to dementia care (e.g. integrating specialist cognition services into primary healthcare) (11)

_____ Improved access to specialist cognition services (e.g. memory clinics, geriatrician) Please specify _____ (12)

_____ Service leadership prioritising a data-driven approach (13)

_____ Additional funding specifically allocated to dementia care and services (14)

_____ Other (please specify) _____ (15)

4.2 How much of a priority is it to improve dementia data collection and management at your service? ***Please move the slider to indicate level of agreement, where 0=not a priority and 5=high priority***

Not a priority	1	2	3	4	High priority	Prefer not to say

4.3 What would help your staff use dementia-related data more effectively? (select all that apply)

- [ ] Education and training in dementia identification/assessment (1)
- [ ] Education and training in data coding process and data literacy and coding (2)
- [ ] Clearer workflows or guidelines (3)
- [ ] Improved software/technical infrastructure (e.g. improved interoperability, streamlined workflows). Please briefly describe what you'd need (4)

_____

- [ ] Access to internal data support (e.g. data/informatics team or staff) (5)
- [ ] Access to external data support (e.g. data consultations) (6)
- [ ] Access to client level data on MCI/dementia (two-way data sharing) (7)
- [ ] Other (please specify) (8) _____

4.4 If relevant to your role, please comment on the most important aspects of data governance in relation to dementia data

_____

4.5 What external data uses would be valuable for your health service *(external data uses involve reporting data to external organisations for monitoring, service design and funding responsibilities, research)*

- [ ] Aboriginal and Torres Strait Islander dementia registry (1)
- [ ] National Aboriginal primary healthcare data collection (2)
- [ ] Dementia-related National Key Performance Indicator (nKPI). National Key Performance Indicators (nKPI) are government reporting indicators that are used to track and evaluate progress towards the goals of the National Aboriginal and Torres Strait Islander Health Plan and the Closing the Gap health outcomes. (3)
- [ ] Other (please specify) (4) _____

4.6 Would you support the development of an nKPI on dementia, if it were co-designed with Aboriginal and Torres Strait Islander primary healthcare providers?

- ○ Yes (1)
- ○ No (2)
- ○ Maybe (3)
- ○ Don't know (4)

4.7 Please provide a brief rationale for your answer in question 4.6

_____

4.8 What type of dementia-related indicator (nKPI) would be most meaningful or useful? Examples might include: documentation of a dementia diagnosis, documentation of cognitive assessments, care plan items

_____

4.9 Is there anything else your service needs to improve dementia-related data collection?

_____

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