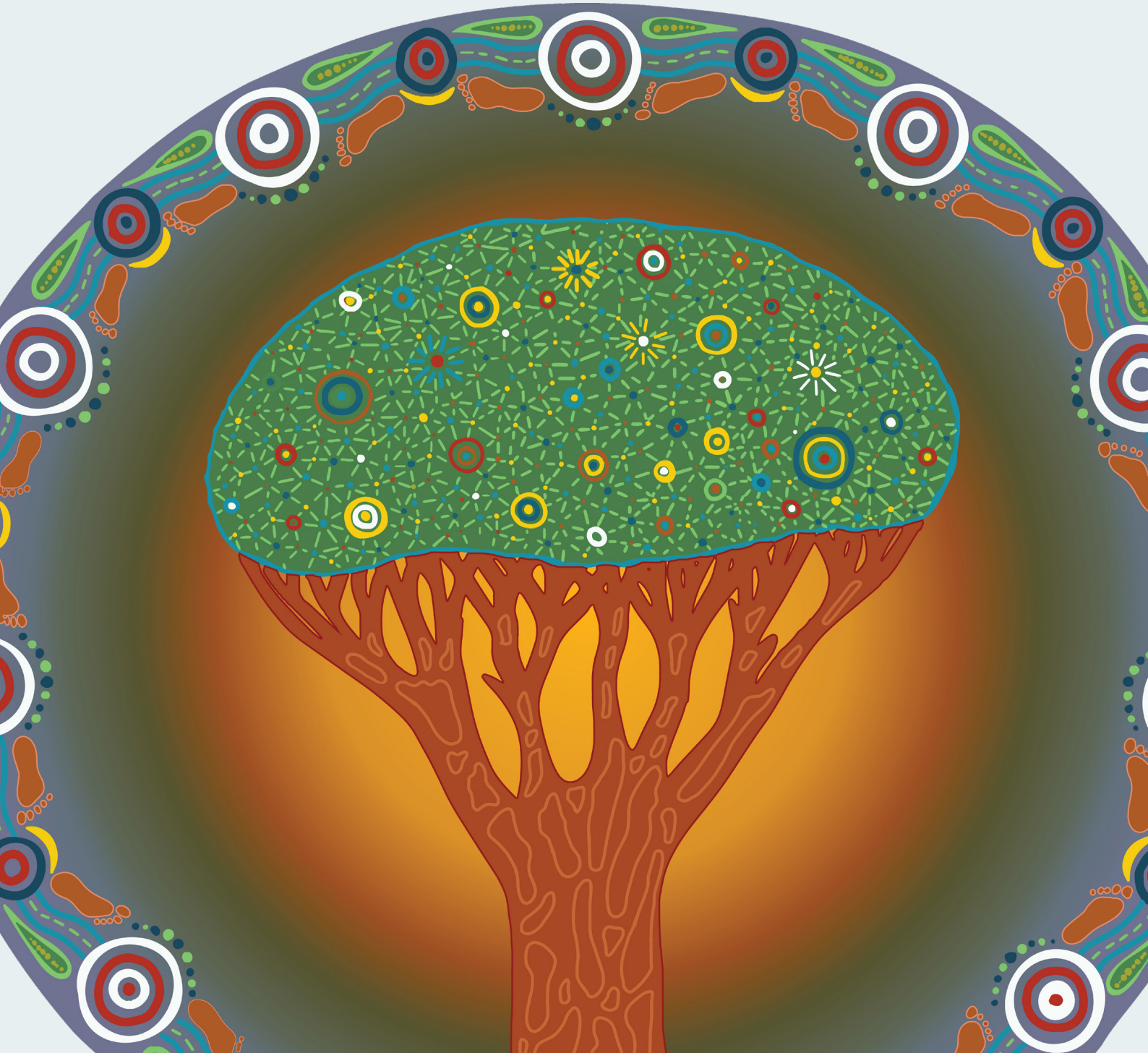
Guide for Culturally Safe Dementia Biomarker and Genetic Research with Aboriginal and Torres Strait Islander Peoples and Communities

A collaborative project facilitated by the OnTRACK Centre of Research Excellence



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Contact details

Department of Medicine, Royal Melbourne Hospital, The University of Melbourne

Level 4, Clinical Sciences Building, Royal Parade

Parkville, VIC 3010

AUSTRALIA

E: ontrack-cre@unimelb.edu.au

W: https://medicine.unimelb.edu.au/school-structure/medicine/research/ontrack

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OnTRACK (Teaching, Research And Community Knowledges): promoting brain health with older Aboriginal and Torres Strait Islander peoples

Contributors

OnTRACK project team: Dawn Bessarab*, Kate Bradley, Janaya Charles*, Jules Ciaccia, Harry Douglas*, Leon Flicker, Jo Hughson, Louise Lavrencic, Dina LoGiudice, Jo Luke*, Huong X. T. Nguyen, Penny O'Brien, Kylie Radford, Ryan Prehn*, Robyn Smith, Sarah Russell, Kylie Sullivan*, Rosie Watson, Adrienne Withall*, and Jesse Zanker.

OnTRACK Community Reference Group members: Dawn Bessarab*, Diane Cadet-James*, Miriam Cleary*, Gail Daylight*, Terrence Donovan*, Harry Douglas*, Tracey Eades*, Daniel Kelly*, Roslyn Malay*, Cassandra Matsumoto*, Dallas McKeown*, Robert Nicholls*, and Mark Wenitong*.

Expert panel: Dawn Bessarab*, Nadine Blair, Carolyn Briggs*, Jeremy Chalke, Miriam Cleary*, Harry Douglas*, David Follent*, Jon Gillies, Azure Hermes*, Daniel Kelly*, Greg Pratt*, Jacob Prehn*, Abe Ropitini*, Betty Sagigi*, Rhiann Sue See*, Slade Sibosado*, Sean Taylor*, Nicole Turner*, and Chenoa Wapau*.

**denotes that the research team member identifies as Aboriginal and/or Torres Strait Islander.*

Graphic design and layout

Designed for the OnTRACK Project by Maar Nation (Gunditjmara) artist Sherry Johnstone

Report design and formatting by Alex Nitsikopoulos

ACKNOWLEDGEMENT OF COUNTRY

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 their 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 Islander peoples and Communities.

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

EXECUTIVE SUMMARY

Context and background

Dementia biomarker and genetic research is advancing rapidly and has the potential to improve the diagnosis, care, and outcomes for people living with dementia. This includes research involving biological samples, imaging and other forms of health data. While these approaches offer promise, they also raise important ethical and cultural considerations, particularly when dementia biomarker and genetic research involves Aboriginal and Torres Strait Islander peoples, including Elders living with cognitive impairment.

In recent years, progress has been made in the field of genomic research with Aboriginal and Torres Strait Islander peoples. National initiatives like the National Centre for Indigenous Genomics (NCIG) and the Australian Alliance for Indigenous Genomics (ALIGN) have established ethical frameworks for genomic research. However, until now, a critical gap remained: there was **no existing guidance specifically addressing *dementia* biomarker and genetic research with Aboriginal and Torres Strait Islander peoples.**

This gap is significant because dementia biomarkers and genetic research raise unique ethical and cultural considerations, including:

- People living with dementia can have fluctuating or impaired decision-making capacity, which needs special consideration, particularly when giving consent for collection, use, storage or disposal of samples or data.
- The use of many emerging biological or genetic markers are not yet validated for clinical care.
- Results of research tests may only indicate likelihoods or risks of developing dementia rather than offering a definitive diagnosis (probabilistic results). This may, in turn, lead to concern or worry.
- Biospecimens may carry deep cultural and relational significance – so their collection, use, storage and disposal need to be very carefully considered.

Why this document was created

The **OnTRACK (Teaching, Research and Community Knowledges) Centre of Research Excellence**, funded by the National Health and Medical Research Council, identified this gap as a Community priority and supported the development of dementia-specific guidance. It is designed to be used by researchers who are planning, conducting, managing or governing dementia biomarker, genetics or genomics research with Aboriginal and Torres Strait Islander peoples.

Methods

This guide was developed through a Community-informed process that integrated existing evidence, lived experience, and expert knowledge. A global scoping review identified core principles for culturally safe biomarker and genomic research with First Nations peoples in Australia, Aotearoa/New Zealand, Canada and the United States. This was complemented by: two yarning circles with Aboriginal and Torres Strait Islander Elders and older adults in regional Victoria; a national expert workshop (Naarm/Melbourne, March 2025) involving researchers, clinicians, Elders, and Community representatives, ACCHO staff, ethics committee members, and policy and governance leaders; and input from additional experts to expand representation. Workshop discussions were facilitated using an adapted World Café approach and analysed using Framework Analysis to generate key themes and guidance. The draft guide was shared with participants in an iterative process to ensure views and recommendations were accurately incorporated.

Key Outcomes

The process informed the development of a dementia-specific, culturally grounded guide comprising **seven guiding principles** and **seven domains of practice** spanning the research lifecycle.

Seven guiding principles	Seven domains of practice
• **Sovereignty & self-determination** • **Trust** • **Relationships** • **Transparency** • **Tailoring approaches** • **Reciprocity** • **Translation, implementation & legacy**	• **Relationships & community engagement** • **Capacity building & reciprocal learnings** • **Governance & policies** • **Research process & consent** • **Samples & biobank structures** • **Ethical communication with participants** • **Community feedback, translation & legacy**

This guide addresses supported and shared decision-making, family and carer involvement, culturally safe consent and communication, Aboriginal and Torres Strait Islander data governance, ethical handling, storage and repatriation of biological samples, and the responsible return and ethical translation of research findings.

Purpose and Use

This guide has been developed to offer evidence and expert-informed guidance for researchers conducting dementia biomarker and genetic research with Aboriginal and Torres Strait Islander peoples. It promotes active consideration and alignment with Community priorities and culturally informed ways of knowing, being and doing.

This guide is grounded in the principle that dementia biomarker and genetic research should involve Aboriginal and Torres Strait Islander peoples at every stage of the research process. The guide emphasises Aboriginal and Torres Strait Islander leadership, genuine partnership, and shared decision-making, including the involvement of families and carers.

Key areas addressed include community engagement, culturally safe consent and communication, governance of biological samples and data, ethical storage and repatriation, and the responsible return and use of research findings. This guide builds on existing national ethical frameworks and extends them to the specific and evolving context of dementia biomarker and genetic research.

This guide is intended to support both researchers and institutions to undertake dementia biomarker and genetic research that is ethically sound and accountable to Aboriginal and Torres Strait Islander peoples. The aim of this resource is to contribute to improved dementia care and outcomes and to more equitable access to the benefits of biomedical research by strengthening culturally informed research practice.

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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 their own histories, cultural traditions, languages, and systems of law and lore. These Communities maintain deep and enduring connections to Country, culture, and kinship systems.

In this guide, the term "Aboriginal and Torres Strait Islander peoples" is used as a collective term while recognising this diversity, and should not be understood as implying that any individual, group, Nation, or community can speak on behalf of all Aboriginal and Torres Strait Islander peoples or communities.

Aboriginal Community Controlled Organisation: A community-controlled organisation that delivers primary health care, prevention and health promotion services to its local Aboriginal Community.

Apolipoprotein E (APOE): a gene with different forms. One form (APOE ε4) can increase the chance of developing dementia, but not everyone with this gene form will develop dementia.

Biobank: A secure facility where biological samples (such as blood, saliva and tissue) and related information are safely stored for future research.

Biomarkers: Measurable characteristics of the body or biological signs that can be measured to provide information about health and disease. In dementia research, biomarkers may include certain proteins, genes or results from brain imaging.

Biospecimen: A biological sample (e.g. blood, saliva, or tissue) collected for medical or research purposes.

Co-creation: Working together with Aboriginal and Torres Strait Islander peoples, communities and researchers to design, lead and guide research from start to finish.

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

Community governance: A process where Aboriginal and Torres Strait Islander peoples lead decision-making about research involving their communities, samples, and data.

Community Reference Group: A group made up of Aboriginal and Torres Strait Islander Community representatives who provide cultural guidance, governance and oversight to ensure that research is culturally safe, respectful and aligned with Community priorities.

Consent - informed: Choosing freely to take part in research after understanding its purpose, risks, and benefits.

Consent - living: researchers regularly check in with participants to confirm ongoing agreement as the study progresses.

Cultural safety: An approach that requires ongoing reflection on cultural assumptions and behaviours, to ensure that research respects Aboriginal and Torres Strait Islander peoples' identities, values, cultures and knowledge systems. Cultural safety involves organisations addressing systemic barriers in order to provide culturally appropriate and responsive care and research environments.

Data: Data is the information collected during research. 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 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 degenerative brain condition characterised by progressive decline in memory, thinking and/or behaviours that affect a person's ability to perform everyday activities. There are many types of dementia, including Alzheimer disease (the most common type), vascular dementia, Lewy Body dementia, and frontotemporal dementia.

DNA: Deoxyribonucleic acid contains the genetic information inside the cells of the body.

Framework analysis: A flexible qualitative analysis method that can be used to sift, chart and organise information in accordance with key issues or themes.

Genetic: Relating to specific genes and how they are passed from parents to children, including how genes influence individual traits (e.g. eye colour) and risks for certain health conditions.

Genetic data: Information from DNA that helps researchers understand health risks, such as dementia, and other inherited traits.

Genetic research: Scientific investigation involving genes or DNA to understand disease risk, mechanisms or inheritance patterns. Genetic research may include the collection of biospecimens for DNA analysis.

Genomic: Relating to the study of all of a person's genes (their genome), including how genes work together and might interact with the environment.

Governance: Structures, policies, and processes that ensure research is accountable, transparent and aligned with a community's values and priorities.

Investigational: A term used to describe a test, treatment or method (like a biomarker) that is still being studied and is not yet approved for regular clinical use for an individual's care or health management. It means that researchers are still learning how well the test, treatment or method works, how accurate it is, and what it might mean for people's health in the future.

KGOWS (Koori Growing Old Well Study): A research study focused on ageing, dementia, and health among Aboriginal peoples in New South Wales, built on strong Community partnerships.

Micro-credentialing: A way of recognising learning from short courses or training that focuses on specific skills or knowledge. Micro-credentials can show that researchers and staff have completed agreed training and may count toward professional development or further study.

Neuroimaging: Techniques such as CT, MRI or PET scans used to visualise the structure or function of the brain, often used in dementia research.

Non-deterministic: Means that having a certain gene or biomarker does not *guarantee* an individual will develop a particular disease — it only shows a person is at an increased risk.

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.

Probabilistic findings: Research results that indicate likelihoods or risk rather than definitive diagnosis; for example, the presence of a particular genetic variant that may increase the risk but not guarantee that a person will develop dementia.

Reciprocity: Two-way, making sure that research benefits are shared, with communities gaining positive outcomes, resources, or knowledge in return for their participation.

Relational accountability: An ethical concept emphasising the importance of maintaining respectful, trusting relationships with communities throughout the research process.

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.

Teach-back method: A communication approach used to confirm understanding in the consent process. The researcher explains information in plain language, then asks the participant to describe the information back in their own words. This helps identify and correct misunderstandings, supports informed and voluntary decision-making, and is especially important when someone's cognition or memory may fluctuate.

Transparency: Being open and honest about why, how, and where research is done, including how samples and findings are used and shared.

Use of data and biospecimens: How a person's data or samples (such as blood or tissue) may be used.

Limited use: using data or samples only for specific, agreed-upon purposes. They cannot be used for anything outside those purposes without additional permission.

Continued use: using data or samples for new research after the original study is finished. Usually allowed only if the person has given permission or a review board approves it.

1. INTRODUCTION

1.1. Context and rationale

Research involving Aboriginal and Torres Strait Islander peoples in Australia is situated within a complex historical context shaped by experiences of unethical research practices, extractive methodologies and lack of Community control or benefit [1, 2]. These legacies have led to profound and ongoing mistrust of research, particularly in areas involving biological samples and genetic material [3]. In response, ethical guidelines such as the National Health and Medical Research Council's "*Keeping Research on Track II" and the Lowitja Institute's "Researching Indigenous Health: A Practical Guide for Researchers"* have provided essential guidance on ethical, culturally safe and respectful research approaches with Aboriginal and Torres Strait Islander peoples and communities [4, 5]. These guidelines emphasise the importance of self-determination, respect, reciprocity, Community governance and Community benefit as foundational principles of ethical research practice. They also align with the four Priority Reform Areas of the National Agreement on Closing the Gap to ensure that culturally safe approaches and the priorities of Aboriginal and Torres Strait Islander peoples are central to research practice [6]. In this context, ethical guidelines promote formal partnerships based on shared decision-making; strengthen research capacity within the Aboriginal and Torres Strait Islander Community-controlled sector; improve access to, and governance of, research data to enable informed community decision-making; and commit to the transformation of organisational systems and practices to ensure culturally safe and responsive research environments [6].

Biomarker and genetic research offer significant opportunities for advancing our understanding of health and disease but also raise unique ethical and cultural considerations. This research often involves the collection of biospecimens (e.g. blood, saliva or tissue) or imaging data (e.g. scans), either for a specific research purpose or for long-term storage in biobanks or repositories to support future studies. While biomarker and genetic research methods are increasingly used in clinical and population health research, their application with Aboriginal and Torres Strait Islander peoples and communities necessitates particular care. This is due to the historical legacy of unethical research practices, enduring sensitivities around the collection and handling of biological samples, the return of research findings that are uncertain or probabilistic (about risk rather than diagnosis), as well as the importance of upholding the principles of Indigenous data sovereignty [7].

Over the past decade, the potential benefits of genomic science for both rare and common diseases have become more widely acknowledged and, in some cases, cautiously accepted by Aboriginal and Torres Strait Islander communities [8-11]. This progress has been facilitated by the development of appropriate governance mechanisms and Indigenous-led research frameworks [4, 12]. National initiatives such as the National Centre for Indigenous Genomics (NCIG) and the Australian Alliance for Indigenous Genomics (ALIGN) have provided important models for ethical and culturally governed genomic research involving Aboriginal and Torres Strait Islander peoples in Australia. Through its educational and engagement program Genomics Our Way, ALIGN has further strengthened Aboriginal and Torres Strait Islander leadership, governance, and data sovereignty in genomics across Australia. In parallel, state-based provisions such as the Queensland Genomics Community Advisory Group (QGCAG) have offered complementary frameworks for Community engagement and ethical oversight in specific jurisdictions [10, 12-14]. While these initiatives offer essential guidance, they do not explicitly address the specific case of dementia research and the emerging role of biomarkers and genetics within this field.

1.2. OnTRACK (Teaching, Research and Community Knowledges) Centre of Research Excellence

The **OnTRACK (Teaching, Research and Community Knowledges) Centre of Research Excellence**, funded by the National Health and Medical Research Council (NHMRC), aims to promote brain health and conduct culturally safe research with older Aboriginal and Torres Strait Islander peoples who are living with or at risk of dementia, and our/their families and carers. A recent scoping review undertaken by the project team identified a critical gap: that no existing guideline comprehensively addresses the ethical and practical considerations of conducting biomarker and genetic research with Aboriginal and Torres Strait Islander peoples *in the context of dementia* [15].

The OnTRACK Aboriginal and Torres Strait Islander Community Reference Group (OnTRACK CRG) supported the plan to address this identified gap as a Community priority. The OnTRACK project has developed this dementia-specific guideline in response and aims to address key areas requiring special consideration [7], including:

1. Research involving individuals with *impaired or fluctuating decision-making capacity.*
2. Collection, storage and *future use of biospecimens, imaging, and genomic data.*
3. Use of *emerging or not-yet-clinically-validated dementia biomarkers* in research settings.
4. *Return of findings, including results that may be clinically significant, unexpected (incidental), or probabilistic in nature—that is, findings which indicate a potential increased risk of disease without confirming a diagnosis.*

1.3. Aims and scope

The purpose of this guide is to provide practical and culturally grounded guidance for Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander researchers, clinicians and research partners engaged in dementia biomarker and genetic research.

This guide is intended to complement existing research guidelines and frameworks, including those developed by the NHMRC [4] and Lowitja Institute [16, 17] and to supplement existing resources such as those provided by the NCIG and Queensland Genomics Community Advisory Group as illustrated in Figure 1. It offers dementia-specific, contextually relevant guidance that centres Aboriginal and Torres Strait Islander Community priorities, promotes Indigenous leadership, and upholds the highest standards of ethical and cultural safety in the design and conduct of research in this rapidly evolving field.

Figure 1: Positioning this guide

1.4. Intended audience

- Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander dementia or biomarker researchers
- Community and advocacy organisations
- Governance groups
- Ethics committees
- Funding bodies
- Policy makers

1.5. Scope and limitations

Aboriginal and Torres Strait Islander peoples comprise more than 250 distinct Nations, language groups, and Communities across Australia, each with their own histories, cultures, governance structures, and relationships to Country. While this guide draws on Aboriginal and Torres Strait Islander leadership, expertise, and community-informed perspectives, the engagement undertaken was extensive but not exhaustive, and did not involve representatives from all Nations or Communities. The guidance should therefore be interpreted as a framework to support culturally safe dementia biomarker and genetic research, rather than as representing the views, preferences, experiences, or priorities of all Aboriginal and Torres Strait Islander peoples, Nations, or communities, or implying authority to speak on their behalf.

2. METHOD & PROCESS

This guide was developed through a multi-stage, community-informed and collaborative process that integrated evidence from a comprehensive literature review with Community and expert opinion.

2.1. Scoping Review

We first conducted a global scoping review to identify core components of culturally safe and ethical biomarker and genomic research with First Nations peoples in Australia, Aotearoa/New Zealand, Canada and the United States of America (USA). This review provided the foundational concepts and principles that informed subsequent community engagement, community-based input and development of the guide [15].

2.2. Yarning circles with Aboriginal and Torres Strait Islander Elders and older Community members

We conducted two yarning circles (a culturally safe form of focus group [18]) in regional Victoria to explore Aboriginal and Torres Strait Islander Elders' and older Community members' understandings and concerns about participation in dementia research involving biomarkers and genetic markers.

2.3. Workshop and guide development

We convened a full-day workshop to seek expert input into the key elements of the framework for dementia research involving biological and genetic markers. Workshop invitees included a diverse expert panel from across Australia, comprising:

- Aboriginal and Torres Strait Islander researchers and clinicians
- Elders and Community and consumer representatives
- Health service staff from Aboriginal Community Controlled Health Organisations (ACCHOs)
- Academic and policy experts with expertise in dementia, data governance and data sovereignty
- Aboriginal and Torres Strait Islander Ethics committee representatives
- Government and governance leaders including representatives from Aboriginal health and health services peak bodies

The workshop was held in person in Naarm-Melbourne in March 2025 and attended by an expert panel of 16 participants. Of the participants, 13 identified as Aboriginal and came from diverse cultural backgrounds, including Arrernte, Bundjalung, Boonwurrung, Kamilaroi, Worimi, Gimuy Walubara Yidinji, Gunnai, Quandamooka, Waanyi, Palawa, Mutti Mutti, Wemba Wemba, Gurindji, Bardi Jaw (Bard), and Yindjibarndi peoples. There was representation from community, consumer, clinical, research, policy, and governance sectors. This diversity reflects a wide range of lived experiences, professional expertise, and cultural knowledges.

Torres Strait Islander participants representing Torres Strait Islander Communities were unable to attend the workshop in person; however, Torres Strait Islander leadership and perspectives informed other stages of the guide's development, including review and feedback on draft framework components. The guide should therefore be interpreted in relation to the specific contributors, expertise, and governance processes involved in its development, rather than as representing the views, preferences, experiences, or priorities of all Aboriginal and Torres Strait Islander peoples, Nations, or communities.

A modified World Café methodology [19] was used to support inclusive, small-group dialogue and reflective discussion. This methodology promotes meaningful yet informal, relaxed small-group discussions—a conversational style that aligns closely with yarning practices, making it suitable in the context of Aboriginal and Torres Strait Islander health research [18, 19]. The methodology for the project was discussed with and endorsed by the OnTRACK CRG as being culturally appropriate [20].

Data generated in the workshops was in-depth researcher notes and memos documenting the content of discussions. A framework analysis approach was used to code workshop data into a matrix using both pre-defined categories (based on themes identified from the scoping review and yarning circles) and novel themes [21]. This structured approach supported the development and refinement of the draft guide. Excerpts from the workshop are included in the guide to illustrate key discussion points and practical insights reflecting the voices of expert Aboriginal and Torres Strait Islander participants in this research. Although no Torres Strait Islander experts were able to attend the workshop in person, several were invited to provide input on the guide during the development phase, as an extension of the workshop process. The expert group, including Torres Strait Islander researchers, reviewed and refined the draft guide in an iterative process. A visual summary of the development process is provided in Figure 2. The methodology for the World Café and data analysis are detailed in Appendices 8.3 and 8.4.

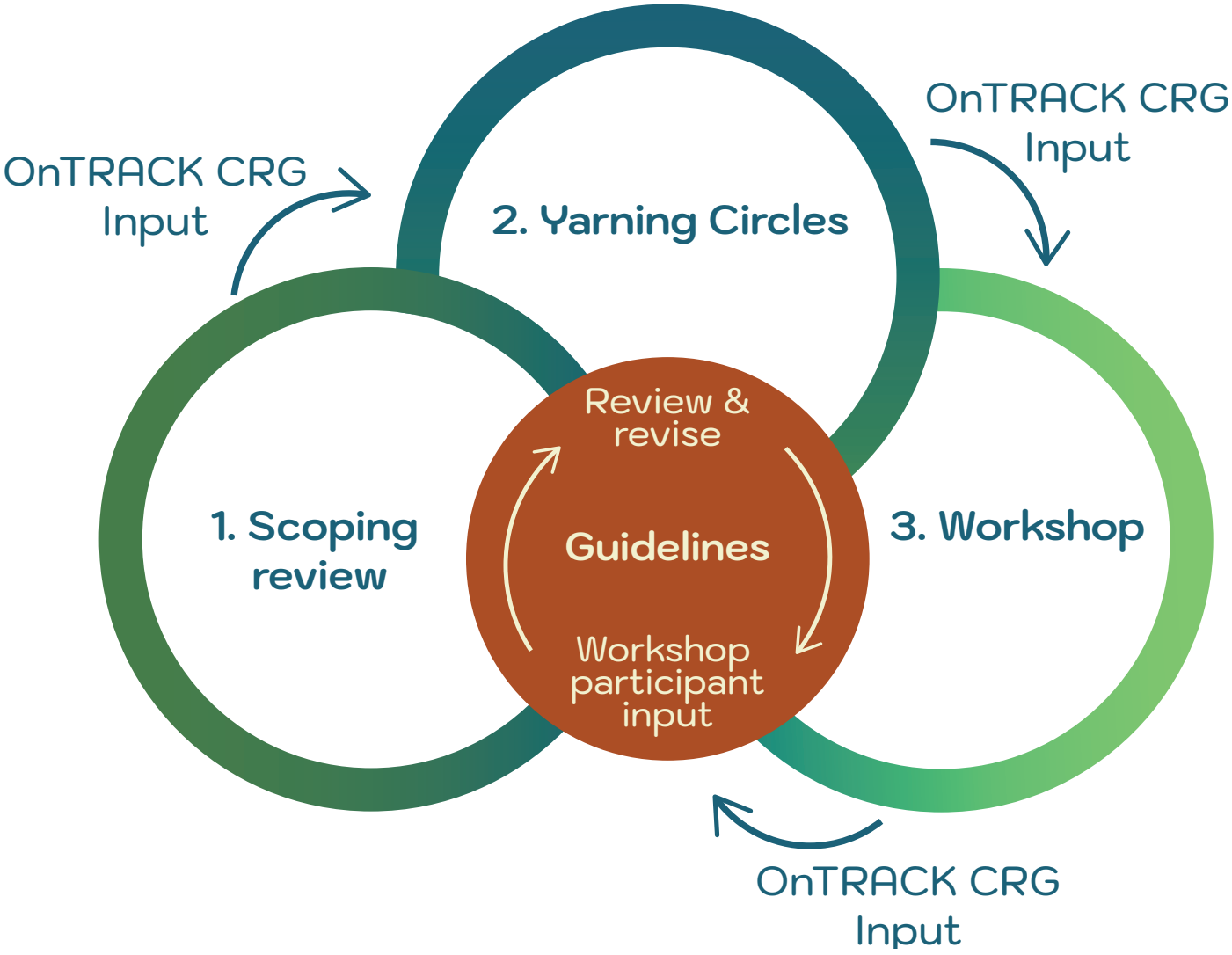


Figure 2: Biomarker Guide development process

Notes: The Community Reference Group for the OnTRACK research program played a key governance role, providing cultural oversight and input throughout the development of this guide.


zoom

3. GUIDE FOR CULTURALLY SAFE BIOMARKER AND GENETIC DEMENTIA RESEARCH

The guide is structured around Guiding principles and Domains of practice (Figure 3), which together provide a visual and conceptual framework to support culturally safe and ethical dementia research involving biomarkers and genetic data with Aboriginal and Torres Strait Islander peoples and communities. These were developed through a multi-stage process, integrating evidence from the scoping review with knowledge shared through yarning circles and the national expert workshop.

Seven guiding principles were identified as essential to inform all stages of the dementia biomarker and/or genetic research process:

1. Sovereignty & self-determination
2. Trust
3. Relationships
4. Transparency
5. Tailoring approaches
6. Reciprocity
7. Translation, implementation & legacy

The Domains of practice comprise seven interrelated domains that span the entire dementia research process involving biospecimens, genetic material, and associated data—from conceptualisation through to interpretation and dissemination:

- Relationships & community engagement
- Capacity building & reciprocal learnings
- Governance & policies
- Research process & consent
- Samples & biobank structures
- Ethical communication with participants
- Community feedback, translation & legacy

Each domain is essential and interconnected, mirroring the cyclical and holistic nature of ethical Aboriginal health research. This guide reinforces that best practice in dementia research is not solely defined by scientific rigour, but importantly, by enacting cultural safety, non-Indigenous researchers showing cultural humility (i.e. for non-Indigenous researchers to be humble, listen with a willingness to learn about and from Aboriginal and Torres Strait Islander knowledges), building respectful partnerships, and fostering enduring benefits for communities.

The model honours the strength and continuity of Indigenous knowledge systems. It reflects the importance of relational accountability and the need for culturally grounded foundations that guide ethical research practice from initial engagement through to lasting legacy.

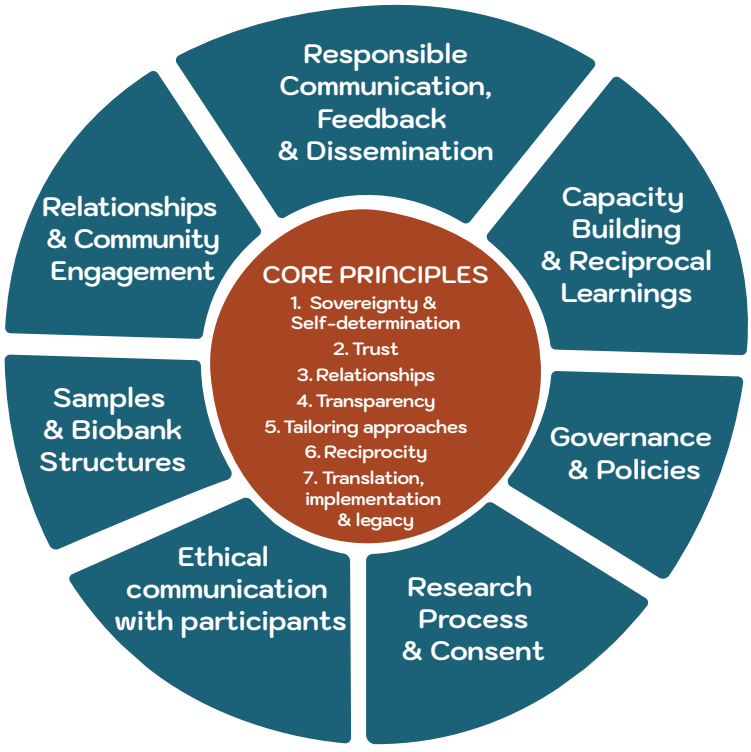


Figure 3: Research Model

4. GUIDING PRINCIPLES FOR DEMENTIA BIOMARKER AND GENETIC RESEARCH

1) Sovereignty and self-determination

Definition: Research must reflect the sovereignty and self-determination of Aboriginal and Torres Strait Islander peoples by responding to community-identified and defined priorities and being grounded in local leadership and governance.

Relevance: Dementia biomarker and genetic research must be driven by Aboriginal and Torres Strait Islander peoples and communities—not only in identifying research questions, but in shaping how research is governed, designed, conducted, and disseminated. Upholding sovereignty means respecting the right of Aboriginal and Torres Strait Islander peoples and communities to control their data (data sovereignty and ownership), biospecimens, and knowledge systems throughout the research lifecycle. Research that is not co-designed with Aboriginal and Torres Strait Islander leadership, or that fails to address clearly defined Community needs, risks replicating extractive practices and undermining trust, autonomy, and cultural safety.

2) Trust

Definition: Trust is the foundational element of ethical research and must be earned through sustained, respectful Community involvement.

Relevance: In the context of dementia biomarker and genetic research, trust requires acknowledging historical harms, demonstrating cultural humility, and ensuring transparent communication. Building trust between communities and researchers takes time, enables meaningful participation and supports shared decision-making across the research lifecycle.

3) Relationships

Definition: Ethical research is built on strong, respectful, and enduring relationships with individuals, families, communities, and Aboriginal Community-controlled organisations and stakeholders.

Relevance: Relationships are not transactional but relational and reciprocal. Long-term partnerships support co-design, enhance cultural safety, and ensure that research aligns with Community values, priorities and cultural protocols.

4) Transparency

Definition: Transparency means openly communicating the aims, methods, risks, and implications of research, including the limitations of emerging scientific tools.

Relevance: Dementia biomarker research can be complex and it is essential that researchers take the time, using appropriate approaches (e.g. the teach-back method), to ensure that people clearly understand the difference between tests for research and tests for clinical care. Researchers need to ensure that people fully understand what will happen to their biospecimens and data. Transparency underpins informed consent and accountability, particularly when dealing with uncertain or investigational findings.

5) Tailoring approaches

Definition: Research processes must be flexible and adapted to the cultural, cognitive and contextual needs of individuals and communities.

Relevance: Tailoring includes listening to Community priorities; communicating using plain language, storytelling, yarning, visual aids, and enabling supported decision-making. This is particularly important when engaging participants with impaired or fluctuating cognition or other health or literacy needs.

6) Reciprocity

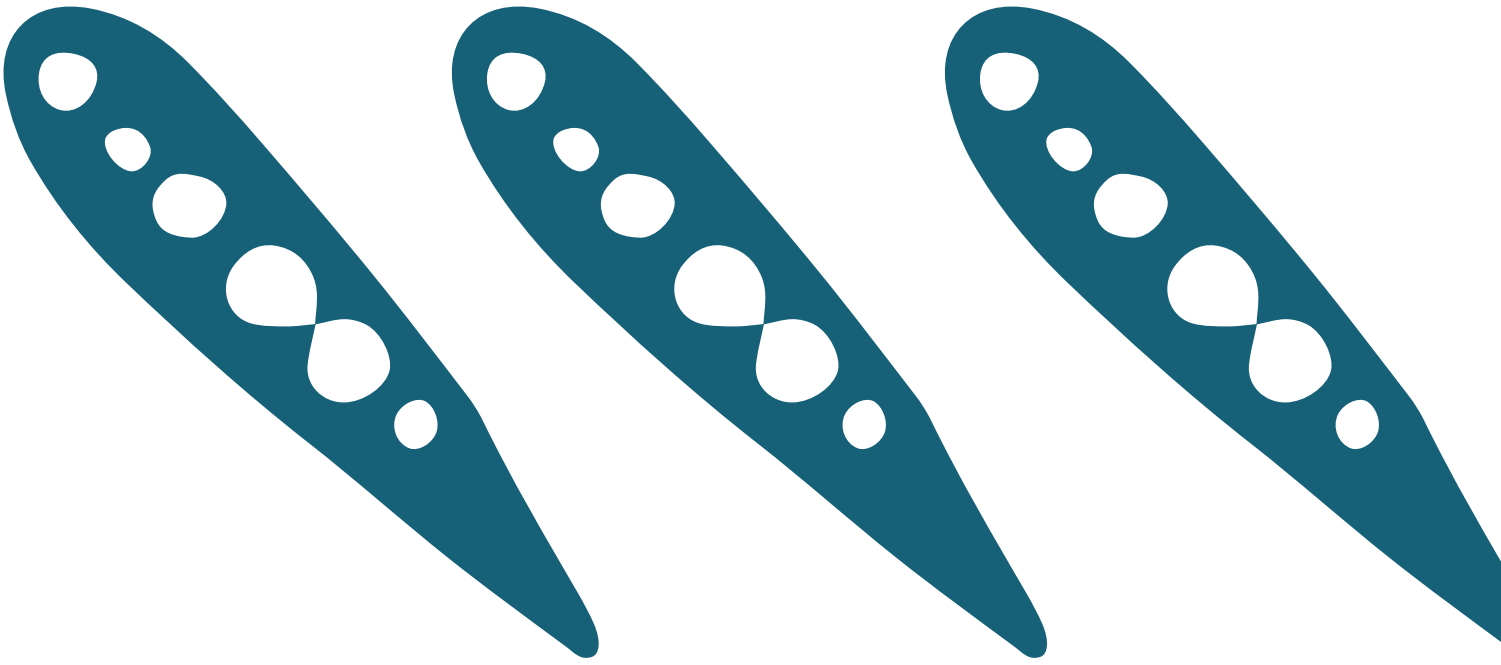
Definition: Ethical research involves reciprocal benefit not just data extraction. Communities must gain tangible value from participation.

Relevance: Reciprocity and reciprocal benefit are not exclusive to health benefits and may take many forms including education, micro-credentials, health or service improvements, employment pathways, or other community-identified benefits. Reciprocity honours the contributions of participants and reinforces mutual respect. Reciprocity also includes ensuring that research findings and outcomes are actively and openly shared with Community in ways that are meaningful and address Community priorities.

7) Translation, implementation & legacy

Definition: Research must leave a lasting and positive legacy for communities, through the translation and implementation of findings into accessible resources, meaningful practice and sustainable change.

Relevance: Translation and implementation involves converting research knowledge into culturally appropriate outputs and ensuring these are available for adoption into practice to benefit communities. This includes informing service development, policy, funding models, or Community knowledge and understanding. A sustainable research legacy includes strengthened local capacity, integration of new knowledge into existing services, advocacy for services that meet local need and continued partnerships beyond the life of a project. These principles also extend to research that could improve the understanding, diagnosis and/or management of dementia for individuals, carers and families.



PRACTICAL GUIDE FOR RESEARCHERS

This section lays out each domain of the guide, together with a short explanation of why each domain matters when planning, implementing and translating dementia biomarker or genetic research with Aboriginal and Torres Strait Islander people and communities. Under each domain is a set of guiding principles for practice, excerpts from the expert workshop notes and some exemplar action steps. These are not exhaustive, but rather, they give some practical suggestions on what researchers can do to facilitate culturally appropriate research approaches. It is important to read this document as an adjunct to the other relevant guides (see p. 4) and essential to develop actions collaboratively with local partners.

Domain 1: Relationships & Community engagement

Why this matters

Strong, respectful relationships are the foundation of ethical research. In dementia care and genetic research, these relationships must appropriately acknowledge historical harms and affirm cultural ways of knowing, being and doing.

Practice principles

- Build trust over time through transparency, cultural humility, and presence.
- Work in relational ways that involve walking alongside Aboriginal and Torres Strait Islander communities and recognising shared responsibility and accountability.
- Approach research with cultural humility, recognising what researchers do not know and being willing to listen and learn from Aboriginal and Torres Strait Islander knowledges.
- Respect local lore/law and ceremony when entering Community, engaging with Community members or handling biological samples.
- Honour the contribution of biospecimens as gifts with deep relational, cultural, and ethical significance rather than neutral research materials.

Excerpts from the Workshop:

'Authority and responsibility needs to be given to Aboriginal leads and going to Community and doing legwork… [it] is working alongside an Aboriginal team, who have the cultural knowledge, awareness and connection – this is a process of walking side by side.'

'Biggest and most important word I think is humility, knowing you don't know everything and being ok with that [and] listening.'

'Relationships, researchers have got to learn to work through relationships, and that takes time and effort.'

Action steps

- Allow adequate time to build trust with communities in research planning, budgeting and design, recognising that trust takes time and sustained effort.
- Genuinely acknowledge historical trauma and systemic mistrust appropriately and openly early in engagement.
- Commit to research as a two-way knowledge exchange from the outset, rather than presuming researcher expertise, and demonstrate willingness to share, compromise, cooperate, compensate, and respect communities as autonomous research partners. Researchers must really listen, engage and understand the priorities, concerns, and preferences of the Community they are working with.
- Provide a local cultural and Community induction before commencing research activities.
- Work with local partners – cultural experts – to navigate, assist, teach, and support researchers to understand local practices and protocols e.g. Elders, champions, ACCHOs who have good relationships with communities.

- Take responsibility for learning about, and responding to, the changing contexts, needs and priorities of communities throughout the life of the research.
- Tailor communication to Community needs and preferences (e.g. plain language, different media, timing of communication, modes of delivery, engaging local experts to support communication and translation).

Domain 2: Capacity building and reciprocal learnings

Why this matters

True reciprocity means that communities gain from research throughout the research lifecycle, including planning, design, conduct and outcomes.

Practice principles

- Build dementia literacy, biomarker research literacy and health literacy with Community throughout the research process.
- Enable Community ownership of knowledge, recognising Community authority over how knowledge is created, used and shared.
- Invest in researcher capability and cultural safety, including education and upskilling to strengthen cultural understanding and improve the safety and quality of researcher engagement.

Excerpts from the Workshop:

'Indigenous lead is really important – [It's] not just about getting the rubber stamp; the first step of building capacity for non-Indigenous researchers is following the lead of the Aboriginal researcher – even if they don't have the degree, they have the degree and knowledge from the Community.'

'It is essential that all non-Indigenous researchers understand that this is not just research, but this is a journey they're on, this is not just about taking, it's about reciprocity.'

Action steps

- Build dementia and biomarker research and health literacy with Community and consumers including through pre-research engagement and consultation. Learning opportunities should be provided in an appropriate format, use lay terms and be guided by local Community preferences.
- Support capacity building for health workers by strengthening knowledge, skills and provide training for Community members involved in research fieldwork.
- Develop micro-credentials for carers, key support people, and Community health workers, recognising they are often the first point of contact regarding dementia.
- Train Community members to deliver literacy training in areas relevant to the research, enabling them to become the teachers of others within the Community.
- Provide ongoing opportunities for Aboriginal and Torres Strait Islander people to be investigators and authors, and to take lead roles in the research, with training and support offered as needed.
- Embed health literacy capacity building within ACCHOs and engage Aboriginal and/or Torres Strait Islander Health Workers/Practitioners already working with the system.
- Provide adequate cultural training for non-Aboriginal staff e.g. Lowitja's Cert IV Aboriginal and Torres Strait Islander research and Community induction.
- Recognise the value of cultural training that comes from the communities you are working with.

Domain 3: Research process & consent

Why this matters

People living with or at risk of dementia experience fluctuating cognitive capacity and/or health over time. Dementia-related research requires a flexible, responsive and culturally appropriate consent process that centres the person, their family and Community.

Practice principles

- Consent is a living, ongoing process, not a one-time completion of a form, particularly in the context of dementia and cognitive impairment.
- Consent should be revisited at key points across the research process, recognising that understanding, circumstances, and decision-making capacity may change over time.
- Participant preferences must be respected and documented, including preferences about future use, storage, return, or disposal of data and/or biospecimens, and what should occur if the person passes away.
- Supported decision-making is central to ethical practice, with family and carers involved where this aligns with the participant's wishes.
- Informed consent must be genuinely understood, using approaches such as teach-back to ensure consent is informed, voluntary, and meaningful [22, 23]. In Aboriginal and Torres Strait Islander contexts, this can be supported through yarning-based teach-back where information is discussed through relational conversation, storytelling, and checking in, rather than formal questioning [24].
- Consent processes must be tailored to support understanding and engagement of people living with dementia or cognitive impairment.
- Transparency is essential, including being explicit about the purpose of research data/biospecimen collection, particularly where biomarkers are not yet validated for clinical use.

Excerpts from the Workshop:

'Be aware people might think they are compromising their care by not participating [in research].'

'With ethics I know it's hard, all the consent materials, you got to go back…if you want to be true about it, genuine, it's got to be tailored consent.'

'As people can lose the capacity to consent over time, it's important to get in early with consent for research and care plans etc. And that's where collaboration with family and Community around shared decision making is important.'

'You're putting all this burden on these people to go somewhere and do these things, but you're not making it easy for them…the stereotype of noncompliance was reinforced to make the problem lie with Aboriginal people, rather than recognise the shortcomings of the research logistics.'

Action steps

- Work with communities to negotiate the right protocols for consent. Protocols should take into consideration scenarios where capacity for complex decision-making may be compromised.
- Discuss consent early, including exploring participants' wishes regarding consent proxies and future family involvement at later stages of the research or dementia journey.
- Discuss and document participants' wishes for data and biospecimens, including what should occur if they pass away, such as continued use, limited use, return to family/Community, or culturally appropriate disposal.
- Re-consent over the course of research and throughout the dementia journey at key points and/or when cognition/capacity to consent may have changed.

- Tailor consent materials to local needs and preferences e.g. videos and animations; read aloud; pen and paper; technology and digital; flipbooks and illustrations; visual tools; plain language; larger font sizes; storytelling; yarning; engaging trusted staff.
- Provide consent information that participants can take away and refer to, allowing adequate time to consider participation and discuss decisions with family or trusted supports.
- Take an individualised approach – documenting people's wishes, including family or trusted facilitators as appropriate.
- Engage an independent translator where required to support understanding during the consent process.
- Clearly explain the right to say no or withdraw at any time, including who to contact and what the withdrawal process involves.
- Spend sufficient time checking understanding, including through teach-back methods, and clearly explain that agreeing or declining to participate in research will not impact access to care or services.
- Be honest and transparent about what is involved in taking part in research and individual potential benefits and risks.
- Clearly explain the broader purpose, potential impact, and outcomes of the research, as well as what will happen to samples and data generated. Spend the time needed to ensure this is fully understood by the person, their family or Community.

Domain 4: Governance & policies

Why this matters

The goals of self-determination, data sovereignty and strong, culturally grounded governance are essential in this area of research.

Practice principles

- Recognise power imbalances and their impacts on research processes and translation and explicitly engage in practices to realign those imbalances.
- Ensure strong, culturally grounded governance from the outset, based on shared understanding of purpose, impact and benefit.
- Embed accountability across all organisations and partners, recognising that ethical research requires responsibility at every step of the project.
- Centre reciprocity and respect, with research returning tangible and meaningful benefits to communities.
- Uphold sovereignty as an active process, recognising that it requires education, resources and time for communities to understand how sovereignty looks and works in practice.

Excerpts from the Workshop:

'Governance structures need to be developed based on what Community has advised. I think it is the responsibility of the researchers to communicate with the Community they intend to work with and collaboratively build your governance structure for your project with that particular Community…every Community is different… the researchers need to make sure they themselves are held accountable.'

'The safety of the collection…the collection is like Intellectual Property…where does the knowledge go…it's DNA. It's telling the story about your past, but also your future and your kids.'

'When it comes to policies, what we want is for Aboriginal peoples to have control over their data and determine how the data is used.'

Action steps

- Prioritise Aboriginal and/or Torres Strait Islander leadership in research, with projects preferably led by Aboriginal and/or Torres Strait Islander researchers. Where research is led by non-Aboriginal people, ensure they have undertaken appropriate training, developed cultural understanding, and are supported by Aboriginal and Torres Strait Islander co-researchers e.g. ensure that researchers understand what ethics means in an Aboriginal and Torres Strait Islander health context, not just a tick-box exercise but conduct and protocols that make engagement culturally safe and ultimately benefit the research.

- Educate researchers about engagement approaches, how to co-design, differences between governance and sovereignty, and how to share power.
- Collaboratively develop governance structures with communities, recognising that every Community is different.
- Build opportunities for Community members to develop knowledge and skills around governance, data sovereignty, research process, including how to work with University partners.
- Establish internal and external governance structures that hold universities, researchers, and Community partners accountable and ensure transparency, integrity and shared responsibility throughout the research lifecycle.

Domain 5: Samples & biobank structures

Why this matters

Biospecimens can have deep relational and/or sacred significance – it is essential to consider this when establishing and overseeing biobanks or handling, storing or repatriating biospecimens and the data that come from them. Strong protections for privacy, confidentiality and Community control over access to data and samples are essential.

Practice principles

- Co-design approaches and processes for biobanking and data management in partnership with Community representatives and with clear Aboriginal and Torres Strait Islander governance structures.
- Ensure clear, culturally safe, Community and consumer governance.
- Uphold privacy and confidentiality of biospecimens and associated data, recognising the sensitivity of genetic and biomarker information and the potential for harm.
- Respect biospecimens as potentially sacred, recognising their cultural, relational, and spiritual significance, and ensure Aboriginal and Torres Strait Islander agency over decisions about biospecimens is retained throughout the research lifecycle.
- Maintain transparency about the journey of biospecimens from collection, through storage, use and disposal, so participants and Communities understand how samples move through research processes.
- Clearly distinguish sample management processes from data management processes, ensuring participants understand what they are consenting to and how these processes work.
- Uphold Community authority over access, recongising that communities and participants must have the final say on whether researchers may access samples, biobanks or data.
- Plan for uncertainty and change, with contingency arrangements in place from the beginning, anticipating what will happen if the biobank closes or sample storage is no longer possible.

Excerpts from the workshop:

'How do the non-Indigenous researchers treat body parts with respect, it's not just a piece of science, [there] needs to be some sort of ritual about the gift that people have given us; "this is me, and it tells the story of who I am".'

'Regarding biobanks, the Community will want to know where the sample is housed. This type of research is so complex as the data can pass through many hands. There needs to be policies in place that protects the data. It's important to make sure whatever policy you develop with Community to protect the data is applied and upheld by all the organisations that are involved in handling or analysing the data…. And the policy needs to have Indigenous data sovereignty structure or Indigenous governance built in.'

Action steps

- Establish a governance or steering committee that has a majority of Aboriginal and/or Torres Strait Islander members and appropriately remunerate members for their time, expertise and cultural guidance.
- Provide clear information to Community members about where and how samples and data are stored.

- Protect the privacy and confidentiality of biospecimens and associated data, including clear controls on who can access samples and data, how they may be used or shared, and how privacy will be safeguarded across all organisations involved.
- Clearly articulated protocols must be developed for the handling of biospecimens and data from collection, through the data lifecycle, to being returned to Country or destroyed, as per individual/Community instruction.
- Ensure accountability across the data chain, so that everyone involved in the collection, storage, analysis and sharing understands and applies culturally safe practices and principles, with accountability back to Community.
- Provide training for all individuals involved in the collection, storage, and use of samples and data.

Domain 6: Ethical communication with participants

Why this matters

In dementia research, particularly when involving biomarkers and genetic data, communicating individual results raises complex ethical, cultural, and clinical considerations. Many dementia biomarkers are still investigational and not validated for routine clinical use, meaning the significance of test results for individuals can be uncertain.

Returning results without clear clinical or personal benefit may cause anxiety, confusion, or harm — especially when dementia biomarkers being researched are not predictive and do not necessarily mean that someone will develop dementia. Sharing findings of increased dementia risk with someone who has no symptoms may also increase worry without providing diagnostic certainty, particularly in the absence of appropriate counselling, follow-up care, and cultural support.

Practice principles

- Engage Community governance groups prior to commencement of data collection to co-develop the plan with the researchers about what results should be returned, by whom and in what circumstances.
- Return individual results only when there is strong evidence of direct benefit to the participant's health, wellbeing, or decision-making. For example, results may inform care planning, risk reduction strategies, or participation in culturally safe clinical trials. Where results are shared, this must come from an appropriate health professional.
- If results are not clinically validated, researchers should clearly explain this and avoid presenting such results as diagnostic. For example: "The result of this test will not tell us for sure whether or not you have dementia. It will give the researchers a better understanding of how well the test works. It might show if you have more chance of developing dementia, but it won't tell us for sure. We won't know until we test lots of people and look at all the results together."
- Maintain a clear distinction between research findings and clinical information.
- Respect participant control over information sharing, including obtaining explicit consent regarding whether results may be shared with their GP, ACCHO, or other nominated healthcare providers.
- Ensure appropriate supports are in place before returning results. Results should not be returned unless culturally safe clinical, counselling, and community-based supports are available, including access to culturally appropriate education and support resources for participants and families, GP or specialist referrals for further assessment and care, and genetic counselling where relevant.
- Communicate honestly and avoid overpromising, using non-deterministic, strengths-based approaches when discussing research findings.
- Tailor communication approaches based on the participant's needs and stage in their dementia journey — using visual tools, stories, and accessible formats. Also consider gender (of the participants and the researchers) and engaging trusted individuals and/or appropriate health professionals in information sharing.

Excerpts from the Workshop:

'Men's business and women's business, researchers need to be culturally mindful of different statuses and protocols of speaking… each Community has different protocols…some things must be spoken about in privacy or confidentially, not in public.'

'Individual plans need to be in place for each. Put a bit more information and time in for people further along their dementia journeys: show them videos, read them things. We're a visual people.

'One of the things to think about is if you're providing individual results, ask whether you are the best person to communicate the results. Or should it be the GP who usually gives them that kind of information? As the researcher you need to think about whether it's your responsibility.'

Action steps

- Develop communication protocols from the beginning through co-designing with local staff and Community members.
- Specify who communicates results and in what context – for example, clinicians may provide individual feedback, while researchers or trusted Community members may communicate aggregated findings at the Community level.
- Base research and outcomes communication on expressed or identified local Community need.
- Use a Community-preferred language and multiple communicaiton modalities, and adopt strengths-based approach for sharing research outcomes.
- Take a holistic, life course approach where appropriate – promoting broader awareness of dementia, brain health and wellbeing.
- Be mindful of cultural protocols, potential taboos and sensitivities, including the cultural complexities around dementia and the possible implications of a dementia diagnosis for the person, family and Community.
- Recognise and support the cultural load carried by Aboriginal and Torres Strait Islander staff — provide appropriate supervision, resources, and time for reflective practice.
- Build training pathways or micro-credentialing opportunities to strengthen local capacity in genomics and dementia literacy among Aboriginal health workers and practitioners and Community leaders.

Domain 7: Community feedback, translation & legacy

Why this matters

Returning results is an ethical responsibility, and also an opportunity to build understanding and awareness of dementia in culturally meaningful ways.

Practice principles

- Plan feedback and dissemination with participating Communities, research stakeholders and governance bodies from the start.
- Tailor research outputs to life stage, language, cultural context and cognitive ability.
- Develop protocols for returning any distressing or incidental findings with local support.
- Honour community-defined outcomes as well as academic outcomes, including intergenerational teaching and knowledge-sharing approaches such as story, song and dance.
- Engage local champions to maintain trust and guide communication.
- Develop and return resources (e.g., infographics, videos, yarns) that are culturally tailored and translated as needed.
- Embed local research protocols and strengthen existing services through training and capacity building (e.g. ACCHOs).

Excerpts from the Workshop:

Track record is not just about publications in high-impact journals, from a Community perspective it's about relationships, rapport and trust.

Each Community you go to will be different, have a set of overarching rules and then fill that out depending on the specific needs of the Community.

Action steps

- Develop clear reporting and feedback protocols from the outset, shaped and affirmed by Community preferences.
- Provide education and training for both researchers and Community members to support shared understanding, feedback and use of research findings.
- Use co-design and co-creation principles to develop the necessary feedback and implementation resources.
- Plan how the research will give back to the Community.
- Communicate clearly and transparently about any next steps from the research.
- Prioritise Aboriginal and Torres Strait Islander-led Community feedback, particularly involving the participating Community. Check in regularly throughout the research to make sure Community wishes are being incorporated.
- Explore ways to include Community in interpretation and dissemination of research outcomes.
- Plan for implementation, translation and research legacy with Community and research stakeholders from the outset. Develop and enact a plan for sharing research outcomes and advocating for uptake of any resources, tools, new knowledge or approaches that arise from the research.

BEST PRACTICE EXAMPLES

Example 1: National Centre for Indigenous Genomics

The National Centre for Indigenous Genomics (NCIG) offers a leading example of culturally safe, ethically governed genomic research with Aboriginal and Torres Strait Islander peoples. Established as a statutory body under federal law, NCIG is legally accountable and guided by a majority-Indigenous governance board that holds custodianship of the biospecimen collection.

The NCIG model is grounded in enduring relationships with communities. From the outset, it affirms that Aboriginal and Torres Strait Islander peoples are the owners of both the samples and the data derived from them. This principle of sovereignty and self-determination is enacted through a rigorous and respectful process of research approval. A dedicated Community Research Access Committee reviews all applications to access biospecimens, assessing each project on its scientific merit, cultural safety, and Community benefit. Based on these recommendations, the Board may grant provisional approval; however, final permission must come directly from the involved community. This ensures that every research project is ultimately endorsed by those with whom the samples are affiliated.

The NCIG consent process is structured around the principle of "living consent"; that is informed consent is not treated as a single point of agreement, but rather as an ongoing dialogue. Participants are given clear options regarding future use of samples, including preferences for repatriation or destruction. These options are honoured throughout the life of the research and beyond. Education and engagement are continuous, with culturally tailored videos and community-facing resources developed to improve understanding of genetic data and research implications.

In managing its biobank, NCIG upholds strict protocols around sample governance, storage, and use. Community members are fully informed about how and where samples are stored, and clear contingency plans are in place in the event that long-term storage becomes unfeasible. These systems are co-designed and transparently communicated, reinforcing accountability at every stage of the research journey.

By embedding Community authority into decision-making, investing in genomic literacy and upholding strong governance structures, NCIG exemplifies how ethical, Community-led genomics research can be undertaken in ways that build trust, enhance capability, and deliver enduring benefit.

Resources:

1. **National Centre for Indigenous Genomics** (NCIG) – Governance Framework
   Provides guidance on Indigenous-led governance, oversight, and decision-making for genomic and biospecimen research.
   https://ncig.anu.edu.au/files/NCIG-Governance-Framework.pdf
2. **National Centre for Indigenous Genomics** (NCIG) – Ethics Protocol
   Outlines ethical requirements and culturally grounded practices for conducting genomics research with Aboriginal and Torres Strait Islander peoples.
   https://ncig.anu.edu.au/files/NCIG-Ethics-Protocol_21082018.pdf
3. **Australian Alliance for Indigenous Genomics** (ALIGN) – Community Resources
   Community-focused genomics resources supporting education, engagement, and Indigenous data sovereignty.
   https://indigenousgenomics.com.au/resources/community/
4. **Australian Alliance for Indigenous Genomics** (ALIGN) – Genomics Our Way video
   Plain-language video explaining genomics research and Indigenous leadership in genomics in Australia.
   https://www.youtube.com/watch?v=So6dy3R7FAU

Example 2: Koori Growing Old Well Study – Neuroimaging and genetic testing

The Koori Growing Old Well Study (KGOWS) offers a strong example of culturally responsive biomarker research grounded in Aboriginal leadership, community engagement, and ethical practice [25]. The neuroimaging and genetic testing optional component of the broader KGOWS project introduced brain scans (magnetic resonance imaging [MRI] and positron emission tomography [PET]) and Apolipoprotein E (ApoE) genotype into dementia research with older Aboriginal Australians—practices that required careful consultation and culturally safe implementation.

The research team undertook extensive community engagement and pre-consultation, including a planning survey with 213 Aboriginal participants, and a pilot neuroimaging study. These engagements affirmed strong Community interest, with most surveyed participants supporting the inclusion of neuroimaging (74%), genetic testing (75%) and blood samples (82%) in future dementia research [26].

Community feedback was directly integrated into the study design. Neuroimaging and genetic testing were incorporated into the second wave of KGOWS, with key measures in place to support cultural safety. Aboriginal research members established genuine relationships and accompanied participants to scans to ensure that participants felt safe, informed, and supported. Participants' experiences of this research are included as important study outcomes.

Consent materials were adapted for accessibility and understanding, and care was taken to clearly explain the purpose, risks and implications of neuroimaging and genetic testing. Protocols were established for conveying neuroimaging and test results back to participants and their nominated GP, and appropriately managing any incidental findings, following specialist radiologist and geriatrician review.

Strong governance and oversight were provided through Aboriginal research leadership and Community representation, including as co-investigators on NHMRC funding (GNT1151851). Aboriginal researchers were also central in communicating findings, engaging with community, and building long-term relationships to guide translation and legacy. Prior to wider dissemination or publication, the first available genetic study findings [25] were shared with Elders, Aboriginal health service staff and other Community members at a two-day knowledge exchange and capacity-building workshop led by Aboriginal research staff.

The KGOWS neuroimaging and genetic testing studies exemplify how complex biomarker and genetic research can be done ethically and effectively, when Aboriginal researchers lead the work, and cultural safety, community-defined priorities and reciprocal partnerships are embedded throughout the research lifecycle.

OTHER RESOURCES

I. **National Statement on Ethical Conduct in Human Research (NHMRC, ARC & Universities Australia, 2025).** Sets out national guidelines for the ethical design, conduct, and review of human research. Includes specific considerations for research involving Aboriginal and Torres Strait Islander peoples.
Resource: https://www.nhmrc.gov.au/sites/default/files/documents/attachments/publications/National-Statement-on-Ethical-Conduct-Human-Research-2025.pdf

II. **Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders (NHMRC, 2018).** This national guideline outlines the core values—spirit and integrity, reciprocity, respect, equality, survival and protection, and responsibility—that underpin ethical research with Aboriginal and Torres Strait Islander peoples.
Resource: https://www.nhmrc.gov.au/about-us/publications/ethical-conduct-researchaboriginal-and-torres-strait-islander-peoples-and-communities

III. **Keeping Research on Track II (NHMRC, 2018).** Provides practical guidance on applying ethical principles across all stages of the research journey. It supports Aboriginal and Torres Strait Islander peoples and communities to make informed decisions about participating in research.
Resource: https://www.nhmrc.gov.au/about-us/resources/keeping-research-track-ii

IV. **Genomic Partnerships: Guidelines for Genomic Research with Aboriginal and Torres Strait Islander Peoples of Queensland (Queensland Institute of Medical Research Berghofer Medical Research Institute, 2019).** A Queensland-based framework offering culturally safe and Community-informed guidance for genomic research with Aboriginal and Torres Strait Islander peoples.
Resource: https://www.qimrb.edu.au/api/asset/serve/2025-indigenous-health-genomics-guide-v9-web

V. **Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code of Ethics for Aboriginal and Torres Strait Islander Research (AIATSIS, 2020).** A nationally endorsed code built on four principles: Indigenous self-determination, Indigenous leadership, impact and value, and sustainability and accountability.
Resource:https://aiatsis.gov.au/sites/default/files/2022-02/aiatsis-code-ethics-jan22.pdf

VI. **Framework for Governance of Indigenous Data: Practical guidance for the Australian Public Service (National Indigenous Australians Agency, 2024).** A guide aimed at helping the Australian Public Service manage any government-held data about or affecting Aboriginal and Torres Strait Islander peoples.
Resource: https://apo.org.au/sites/default/files/resource-files/2024-05/apo-nid327194.pdf

VII. **Researching Right Way: A Domestic and International Review (NHMRC, Lowitja Institute & AIATSIS, 2020).** Reviews Indigenous health research ethics guidelines across jurisdictions to ensure alignment with principles of cultural safety, accountability, and reciprocity.
Resource: https://www.nhmrc.gov.au/research-policy/ethics/ethical-guidelines-research-aboriginal-and-torres-strait-islander-peoples

VIII. **Researching Indigenous Health: A Practical Guide for Researchers (Lowitja Institute 2011).** Offers practical guidance on conducting ethical, culturally safe Indigenous health research, with a focus on respectful partnerships, community engagement, and meaningful benefit to communities.
Resource: https://www.lowitja.org.au/wp-content/uploads/2023/05/Researchers-Guide_0.pdf

APPENDICES

A OnTRACK CRG members

- **Aunty Dawn Bessarab – Bard (West Kimberley) and Yjindjarbandi (Pilbara) woman** – is Professor and Director of the Centre for Aboriginal Medical and Dental Health at the University of Western Australia
- **Aunty Miriam Cleary – Eastern Arrernte (father) and Gurindji (mother) woman** – is a Family and Community Coordinator with the Advocacy Research Team at Dementia Australia.
- **Aunty Gail Daylight – Kamilaroi woman** – worked in Aboriginal Health for over 30 years and was inducted into the NSW Aboriginal Health Hall of Fame. She has also been an Associate Investigator with NeuRA.
- **Aunty Diane Cadet-James – Gugu Badhun nation of the Valley of Lagoons woman**– is a researcher with the Healthy Ageing Research Team (HART).
- **Uncle Terry Donovan – Gumbaynggirr / Biripi man** – most recently worked with the Aboriginal Health & Ageing Program at Neuroscience Research Australia for eight years as a Knowledge Translation Officer.
- **Co-Chair Uncle Harry Douglas – Gunnai man** – is a cultural advisor and senior Aboriginal Community leader at the Victorian Aboriginal Health Service (VAHS) and senior Aboriginal researcher at The University of Melbourne.
- **Aunty Tracey Eades – Noongar woman** – is an Elder Care Support Coordinator for My Aged Care support and services at VAHS.
- **Uncle Danny (Daniel) Kelly – Mutthi Mutthi and Wemba Wemba man** – has a background in social work with 40 years' experience working with the Victorian Aboriginal Community and is a member of the Elders Voice for Treaty Group.
- **Co-Chair Aunty Roslyn Malay – Yurriyangem Taam Kija woman (East Kimberley)** – is a Senior Project Officer at the University of Western Australia.
- **Aunty Cassandra Matsumoto – Nimanburru / Walman Yawuru woman** – is a senior Aboriginal Research Officer and Equine Assisted Learning (EAL) Practitioner.
- **Aunty Dallas McKeown – Yuwaalaraay woman** – has over three decades of experience in health and wellbeing and is employed at the Council of Remote Area Nurses Australia.
- **Uncle Bobby (Robert) Nicholls – Yorta Yorta, Dja Dja Wurrung and Wadjabalok man** – is a former Director of the Victorian Aboriginal Child Care Agency (VACCA) and a long-serving advocate for Aboriginal Community welfare, cultural knowledge and youth empowerment.
- **Dr. Mark Wenitong – Kabi Kabi tribal group man** – is a medical doctor and a National Mental Health Commissioner.

B Workshop participants

- **Aunty Carolyn Briggs** – Professor Department of Fine Art, Monash – Welcome to Country
- **Jacob Prehn** – Director of Research, Evaluation, and Data Governance, Treaty Authority Victoria
- **Azure Hermes** – Deputy Director of the National Centre for Indigenous Genomics, Australian National University
- **Greg Pratt** – Principal Research Fellow, Central Queensland University
- **Rhiann Sue See** – Geriatrician and Researcher, James Cook University
- **Jeremy Chalke** – Public Health Registrar, National Aboriginal Community Controlled Health Organisation
- **Nadine Blair** – Director of Policy, National Aboriginal Community Controlled Health Organisation
- **Abe Ropitini** – Victorian Aboriginal Community Controlled Health Organisation / The University of Melbourne
- **Jon Gillies** – Public Health Medical Officer, Victorian Aboriginal Community Controlled Health Organisation

- **David Follent** – Senior Project Officer, Agency for Clinical Innovation
- **Nicole Turner** – Chief Executive Officer, Aboriginal Health and Medical Research Council of New South Wales
- **Slade Sibosado** – Manager, Kimberley Aboriginal Health Research Alliance
- **Uncle Danny (Daniel) Kelly** – member of the Elders Voice for Treaty Group and the Aboriginal Health and Medical Research Council Human Research Ethics Committee Elders.
- **Aunty Miriam Cleary** – Family and Community Coordinator, Dementia Australia
- **Uncle Harry Douglas** – Project Officer, The University of Melbourne / Care Coordinator, Victorian Aboriginal Health Service
- **Aunty Dawn Bessarab** – Professor and Director, Centre for Aboriginal Medical and Dental Health, University of Western Australia

Experts who were unable to attend the workshop but provided input to the guidelines:

- **Sean Taylor** – Professor of Aboriginal and Torres Strait Islander Health and Director of Onemda, The University of Melbourne.
- **Aunty Betty Sagigi** – Torres Strait Islander Elder and member of the Healthy Ageing Research Team.
- **Chenoa Wapau** – Torres Strait Islander Community member and member of the Healthy Ageing Research Team.

C Adaptation of the World Café Method for the Expert Workshop

The World Café method is an accepted methodology for facilitating structured, large-group conversations [19]. For this project, the expert workshop used an adapted World Café methodology to create a safe, inclusive, and collaborative environment for discussion. This participatory method was modified to ensure cultural appropriateness and meaningful engagement with Aboriginal and Torres Strait Islander Community representatives alongside academic, clinical, policy, and governance experts, based on the approach described by Lohr et al. (2020) [19].

Purpose of the adaptation

The aim was to bring together diverse voices to guide the development of the biomarkers and genetics guide in the context of dementia. The method was adapted to ensure:

- **Cultural safety** was prioritised at all stages.
- **Equal opportunity** for all participants to share perspectives.
- Integration of **community priorities** with research needs.
- A process grounded in **trust, respect, and relational accountability**.

Key adaptations

1. **Cultural safety and protocols**

- Elders and Aboriginal researchers opened and closed the workshop, including with a Welcome to Country setting a respectful tone.
- Yarning-style conversations were used alongside formal presentations to align with Indigenous knowledge-sharing practices.

2. **Smaller, facilitated discussion groups**

- Participants rotated between small tables, each focused on one domain.
- Each table was co-facilitated by an Aboriginal researcher and a content expert to balance community knowledge and technical expertise.

3. Inclusive participation

- Presentations at the beginning of the workshop laid the foundations and supported participants' understanding of biomarkers and genetics in dementia research.
- Breaks were built into the program to allow informal yarning and relationship-building.

4. Collective analysis and synthesis

- An iterative approach was used to analyse and synthesise data gathered from the workshop to ensure that the final guidelines reflect the collective wisdom of the experts.

D Adapted framework analysis approach

To analyse data from the expert workshop, we used an adapted Framework Analysis approach based on the methodology developed by Ritchie and Spencer (1994) [27]. This is an applied qualitative method that uses a structured and systematic process to organise and interpret data while retaining strong links to participants' voices and experiences.

The approach involves five interconnected steps [20]:

1. **Familiarisation** – reviewing notes and transcripts to gain an overall understanding of key ideas and discussions.
2. **Identifying a thematic framework** – developing a framework of pre-defined categories informed by the scoping review and yarning circles, while allowing space for new themes.
3. **Indexing (coding)** – coding the workshop data using these themes.
4. **Charting and summarising** – organising data into a matrix to enable comparison across participants, cases, and themes.
5. **Mapping and interpretation** – identifying relationships, patterns, and explanations across themes and subthemes.

This structured analysis was conducted independently by three research team members, then synthesised and discussed collaboratively in an iterative process with the broader research team of Aboriginal and non-Aboriginal researchers. This approach balanced the need for summary and synthesis with the importance of retaining the richness and meaning of the original data. The results were refined through multiple feedback cycles involving both the research team and expert workshop participants.

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