

AAG
Australian Association of Gerontology

ATSIAAG
Aboriginal and Torres Strait Islander Ageing Advisory Group

Knowing and Doing Better

Delivering stronger collaborations in First Nations Health and Ageing

2026

Acknowledgement of Country

AAG acknowledges Traditional Owners of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures, to Elders past and present, and to all Aboriginal and Torres Strait Islander Peoples, including members of the Stolen Generations.

For further information, see the AAG Aboriginal and Torres Strait Islander Ageing Advisory Group.

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Knowing and Doing Better: Delivering stronger collaborations in First Nations Health and Ageing

1. Introduction and background

Aboriginal and Torres Strait Islander (First Nations) Peoples continue to sustain vibrant, strong and fulfilling communities while Aboriginal and Torres Strait Islander Elders and Older people have been central to maintaining Culture, language and connections across generations. Despite these achievements and ongoing contributions, many Aboriginal and Torres Strait Islander Elders and Older people continue to confront inequality, political exclusion, the impacts of intergenerational trauma and institutional racism. These impacts and exclusions limit the intended efficacy of research projects, policy and programs. In this paper, we argue that improving the quality and impact of ageing policies and research is not only about improving engagement with Aboriginal and Torres Strait Islander Peoples, it also means shifting power so that research is informed, governed and evaluated by Aboriginal and Torres Strait Islander people, including Elders, community-controlled organisations and Aboriginal and Torres Strait Islander researchers.

Currently the Australian national research and policy landscape features significant investment in Aboriginal and Torres Strait Islander wellbeing. For example, signed in 2020, the National Agreement on Closing the Gap ('National Agreement') was meant to reset the ways Australian governments worked with Aboriginal and Torres Strait Islander Peoples, but a 2024 review by the Productivity Commission

> "…shows that governments are not adequately delivering on this commitment. Despite some pockets of good practice, progress in implementing the Agreement's Priority Reforms has, for the most part, been weak and reflects tweaks to, or actions overlayed onto, business-as-usual approaches. The disparate actions and ad hoc changes have not led to improvements that are noticeable and meaningful for Aboriginal and Torres Strait Islander people. This raises questions about whether governments have fully grasped the scale of change required to their systems, operations and ways of working to deliver the unprecedented shift they have committed to." (Productivity Commission, 2024, p.3)

Similarly, in 2024–25, the National Health and Medical Research Council (NHMRC, 2025) spent $78.45 million on Aboriginal and Torres Strait Islander health research across 217 active grants while 8.3% of its Medical Research Endowment Account (MREA) was allocated to Aboriginal and Torres Strait Islander health research. The Australian Research Council (ARC, 2025) funded 16 Aboriginal and Torres Strait Islander led projects totalling $18.4 million. These projects include building capacity and workforce in Aboriginal and Torres Strait Islander health and research, promoting Aboriginal and Torres Strait Islander leadership and realising benefits for community.

Taken together, these initiatives indicate that while there is a stated commitment to eradicating the inequalities in health and wellbeing outcomes between Indigenous and non-Indigenous populations in Australia, and funding into Aboriginal and Torres Strait Islander specific research is significant, there remains a disconnect between the intention of policy and research and the delivery of outcomes in line with the Closing the Gap National

Agreement. This raises the question of what needs to shift in the policy and research environment to better support Aboriginal and Torres Strait Islander health and wellbeing. This question is particularly pertinent for Elders and Older Aboriginal and Torres Strait Islander people who survive significant periods of discrimination and subsequently face higher risks of developing chronic diseases and earlier mortality than other Australians (AIHW, 2025) despite these investments and initiatives.

In the 21st century it has been increasingly acknowledged that mainstream research and practices devalue Aboriginal and Torres Strait Islander knowledge systems. This has been compounded by research characterised as being conducted *on* rather than *with* Indigenous Peoples globally (Smith, 2021). Aboriginal and Torres Strait Islander communities' distrust of mainstream research is said to be the result of this objectification in research, and concomitant devaluation and exclusion from decision-making about who and what counts as undertaking quality research (Humphery, 2001). In this paper we explore ways that research can respectfully engage with Aboriginal and Torres Strait Islander communities, while also highlighting practices that continue to marginalise Aboriginal and Torres Strait Islander ways of *knowing, being and doing* (NHMRC, 2005).

Ahead of the 2024 AAG Conference in lutruwita / Trouwerner (Tasmania), we held the annual National Aboriginal and Torres Strait Islander Ageing Advisory Group (ATSIAAG) Workshop on Tuesday, 11 November. It was a day of panel discussions, presentations, workshops and yarn ups dedicated to Aboriginal and Torres Strait Islander ageing. One popular session featured a panel discussion entitled *"Knowing, being and doing: Better collaborations in ageing"* with speakers experienced in research collaborations between Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander organisations. Featured speakers included Uncle Leslie Dick (University of Tasmania), Prof Linda Deravin (University of Southern Queensland) and Prof Leon Flicker (University of Western Australia).

A key takeaway from this panel discussion is that whilst the message of partnership and authentic engagement is becoming known in research and policy circles, a common criticism across the panel was that in practice non-Indigenous researchers were often ignorant of the structural barriers and inequalities that inform research and policymaking spaces. Thus, Aboriginal and Torres Strait Islander 'health deficits' were often the focus of research and policymaking projects, but the role of colonisation or racism are reified or unacknowledged. For example, one challenge facing many Aboriginal and Torres Strait Islander researchers is that Western colonised institutions do not recognise Aboriginal and Torres Strait Islander practices as being of equal value. This means the narrative of Aboriginal and Torres Strait Islander failings obscures the functions of racism and fail to genuinely engage communities as equal partners.

To engage equally, research must substantially involve those whose lives it seeks to represent or understand. Currently one preferred approach is through engaging with Aboriginal Community Controlled Organisations (ACCOs) as sites of community self-determination and self-governance. Yet the research field is one of its own ecosystems with politics, knowledges and practices that may not fit within ACCOs' objectives and priorities. Moreover, the research ecosystem may subsume that which makes ACCOs places of community control, if there are not enough safeguards or at least research governance and infrastructure oversight systems in place prior to a research partnership or project being

initiated. To gauge the interest and preparedness of ACCOs to enter into the formal research ecology, we engaged with Elders, Aboriginal and Stolen Generations Community Controlled Organisations and Aboriginal aged care sector stakeholders at the 2026 NSW Aboriginal Aged Care Forum, to investigate and confirm what knowledge about research governance, practices and knowledge gaps exist in the sector that might need attending to before ethical equitable research partnerships can occur.

In this paper we first present a summary of the expert panel discussion in Hobart 2024, followed by a brief exploration of strategies for change and partnership in the policy landscape. We then summarise and outline the sector feedback we received at the NSW Aged Care Forum in 2026, before reiterating the recommendations shared with us about ways to make the research environment more supportive of Aboriginal and Torres Strait Islander ways of knowing, being and doing.

2. Summary of lutruwita / Trouwerner 2024 panel discussion

2.1 Centrality of spirit in Aboriginal ways of knowing, being and doing

The panel discussion opened with local Elder, Uncle Leslie Dick highlighting the centrality of spirit and mother earth in his life and actions. Spirit is something often framed out of discussions about research and ethical engagement considerations, despite being an established and central value in the first NHMRC *Keeping Research on Track* model (2005, p.8).

There are research endeavours working to foreground spirit and its importance to promoting Aboriginal and Torres Strait Islander people's wellbeing in later life, such as initiatives within the Good Spirit Good Life body of work (*Institute for Aboriginal Wellbeing Research*, n.d.). This centrality of spirit overlooked by Western researchers was echoed by panellists who reminded audience members that Aboriginal and Torres Strait Islander Peoples have been doing science and research since time immemorial, but whose knowledge and traditions are poorly recognised in Western systems.

2.2 Valuing diverse knowledge traditions

A challenge facing many Aboriginal and Torres Strait Islander researchers is that in Western colonised institutions these research practices are not recognised as being of equal value. This unequal footing can be seen in examples like bush medicines and seasonal burning practices, phenomenon being normalised and formalised in the 21st century. The uptake of Aboriginal and Torres Strait Islander traditions in mainstream settings is the result of two converging processes. The first is the persistence of Aboriginal and Torres Strait Islander communities resisting colonial controls and suppression of Aboriginal and Torres Strait Islander cultural practices, and the ongoing advocacy for their continuation. The second is that recognition has been granted because these practices have been validated in Western science. This means Aboriginal and Torres Strait Islander knowledges are still not being recognised on their own terms, instead where it is recognisable in Western science it might be promoted or adopted. Thus, only some Aboriginal and Torres Strait Islander knowledges are being celebrated in research and policy with recognition being granted upon validation through the paradigm of Western science.

2.3 Deficits based research and obscuring coloniality

Similarly, there is a lot of research and policy interest in 'fixing' Aboriginal and Torres Strait Islander 'deficits', without reflection on how these 'deficits' are constituted within a settler colonial society. A common criticism across the panel was that non-Aboriginal and Torres Strait Islander researchers were often ignorant to local colonial histories and the history of Australia which underpins contemporary Aboriginal and Torres Strait Islander 'deficits'. Panellists called for two practices to challenge the 'deficits' model of Aboriginal and Torres Strait Islander health and ageing research.

The first practice suggested by panellists, is that research needs to be focused on the strengths in many communities and strategies for surviving and thriving practiced in daily life. The second practice is learning the local history of the area to challenge the dominant narrative of Aboriginal and Torres Strait Islander failings to prevent research which obscures the legacies of colonialist destruction. The combination of these two approaches is aimed at understanding the local context and making central those priorities and strategies within Aboriginal and Torres Strait Islander communities that promote wellbeing and support local traditions and cultures.

2.4 Power imbalances in research structures

Furthermore, panellists talked about ways the wider structure of the research and academic industry often encourages culturally unsafe practices which contribute to harm and disempowerment in Aboriginal and Torres Strait Islander communities. Unsafe cultural practices are encouraged through the imposition of short project timelines and incentivising research outputs that do not serve community interests, such as rewarding publications in high-ranking academic journals more than promoting the delivery of outcomes and materials produced with community aspirations in mind. Adding to this is the uneven incorporation of 'checks and balances' in competitive research grant application rounds where community engagement is undervalued, and tokenistic leadership structures inadvertently rewarded. Currently, the structure of research funding and grant awards are derived from Western centred values, which are focused on individual achievement. This contributes towards rewarding an impoverished understanding of Aboriginal and Torres Strait Islander leadership while sidelining community priorities.

2.5 Pressures on Aboriginal and Torres Strait Islander communities in research

These conflicting structures reproduced at the highest levels of research and academia have flow on effects in how research is conducted at the ground level with communities. That is where research teams working in partnership with local organisations must juggle the research expectations of academic regulatory and funding bodies, whilst also meeting community needs. This can rapidly escalate the amount of engagement and project work researchers in this field must undertake, requiring more time and resources when compared to similar projects in mainstream settings. Thus, research budgets and timelines rarely reflect the realities of Aboriginal and Torres Strait Islander community life and instead reflect Western centric research processes.

Other panel members talked about the impact of working as community members in research projects. These roles are designed to facilitate engagement at the local level in

research projects but can fail to consider the cultural and familial responsibilities expected of Aboriginal and Torres Strait Islander staff working in their communities. Too often it is these local staff members who are at the face of the struggle working to deliver outcomes in two very different systems of values and obligations. Thus, leaving Aboriginal and Torres Strait Islander staff acting as research liaisons to negotiate competing priorities and requirements of Aboriginal and Torres Strait Islander and Western centred systems.

2.6 Panel conclusions

This panel brought to the fore a tension not well explored in Australian policymaking and research settings – how do we create research environments that are conducive to Aboriginal and Torres Strait Islander leadership in a substantive rather than tokenistic way? This is especially pertinent in terms of research and policy focused on healthy ageing and older people owing to the importance of Elders and Older people in Aboriginal and Torres Strait Islander communities. The living experience of discrimination and intergenerational trauma in Older Aboriginal and Torres Strait Islander Peoples further complicates these relationships. It is therefore imperative that research with Elders and Older Aboriginal and Torres Strait Islander people is attentive to the legacies and practices of colonial harms, the important role Elders and Older people play in Aboriginal and Torres Strait Islander communities, and the likelihood of complicating factors (health, socioeconomic, political and cultural) in these contexts. Furthermore, research needs to be designed with Aboriginal and Torres Strait Islander researchers, people and communities as the authorities and agenda setters, not the subordinates or subsidiaries to Western centric systems.

3. Strategies for change and promises of partnership

Research and policy can meaningfully improve the lives of Aboriginal and Torres Strait Islander Elders and Older people only when they reflect and respond to community priorities. The National Aboriginal and Torres Strait Islander Aged Care Framework (Australian Government Department of Health, Disability and Ageing, 2025) envisions that

> "Older Aboriginal and Torres Strait Islander people age well by having their spiritual, physical and mental health needs met through holistic, high-quality and culturally safe aged care that promotes wellbeing, delivers trauma aware and healing informed responses and empowers connection to culture, family, community and Country or Island Home." (p.4)

To do this, the fourth of the four guiding principles to the Framework states that:

> "Evidence based on the lived experience of Aboriginal and Torres Strait Islander people will be used to drive aged care reform for Aboriginal and Torres Strait Islander people" (p.4)

While we agree with the sentiments expressed in the overall vision of the Aboriginal and Torres Strait Islander Aged Care Framework, and that evidence ought to be based on the lived experience of Aboriginal and Torres Strait Islander people (as highlighted above in section 2), concerns remain about how that evidence is framed and generated. Basing research on lived experience is not enough if it is reinterpreted through a Western centred research lens. Instead, a concept that might help transform the largely uneven context of most research partnerships is to promote and engage in practices that foreground self-

determination in research. Self-determination as opposed to partnership means that Aboriginal and Torres Strait Islander Peoples, perspectives and priorities are informing the research from inception to completion.

Since the earliest of rights movements in Australia, there have been calls for Aboriginal and Torres Strait Islander self-determination. These calls have been met with uneven responses from Australian institutions, despite self-determination for Aboriginal and Torres Strait Islander Peoples being part of Australia's obligations under international law since 2009.

In 2009, Australia became a signatory to the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) which states that

> "Indigenous Peoples have the right to self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development" (Article 3 UNDRIP, United Nations, 2007).

Self-determination, according to the Australian Human Rights Commission (AHRC) is "…an ongoing process of ensuring that [P]eoples are able to make decisions about matters that affect their lives" (2023, p.2). Without self-determination, it is not possible to enter partnership on equal terms. Only when self-determination is realised can the partnership become meaningful.

Currently, Closing the Gap is the most comprehensive policy priority agreement at both State and Commonwealth levels of government regarding the health and wellbeing of Aboriginal and Torres Strait Islander Peoples. Aboriginal and Torres Strait Islander people have long advocated for a decision-making role in policies, programs and services to achieve better outcomes. In recognition of the inherent strengths of Aboriginal and Torres Strait Islander communities and organisations, all governments have committed to a new era of partnership and shared decision making under the new National Agreement on Closing the Gap.

Transforming government organisations is Priority Reform 3 in the Closing the Gap National Agreement. Mechanisms to achieve this transformation include: identifying racism, improving engagement, supporting culture and embedding cultural safety, and working with Aboriginal and Torres Strait Islander people.

Similarly, the National Aboriginal and Torres Strait Islander Health Plan 2021 – 2031 (Australian Government Department of Health, Disability and Ageing, 2021) and the National Aboriginal and Torres Strait Islander Aged Care Framework (Australian Government Department of Health, Disability and Ageing, 2025) also commit governments to work in partnership with Aboriginal and Torres Strait Islander people to drive solutions and to build the community controlled health sector. To do this the health plan gives recognition of

> "…the historical and ongoing impact that experiences of interpersonal and institutional racism in mainstream health settings have on Aboriginal and Torres Strait Islander people's health and empowerment. Identifying and eliminating this racism is key to better access across the whole health system and to improving health outcomes." (p.10).

Further affirming the commitment made in the Closing the Gap framework that

> "Systemic and structural transformation aligns with Priority Reform Three of the National Agreement by ensuring accountability and better responding to the needs of Aboriginal and Torres Strait Islander people" (p.10).

Thus, the National Agreement on Closing the Gap makes clear, that in some areas it is known that there is a need for transformation and change on the part of government and systems to create meaningful partnerships.

3.1 Lessons from Aboriginal Community Controlled Organisations (ACCOs)

In health delivery, ACCOs are reportedly increasing their services in terms of primary health care deliverables as well as seeing a growing number of Aboriginal and Torres Strait Islander clients (Australian Institute of Health and Welfare [AIHW], 2016). Whilst noting the difficulty in quantifying this comparison, many cite the success of ACCO health providers in delivering a wider range of services in complex conditions (Mackey, et al., 2016; Fambach, et al., 2017; Pearson, et al., 2020). One of the defining features of ACCOs, beyond cultural safety, is that they are spaces that are community controlled and examples of self-determination in action. What we can learn from this model and apply to research is not only the importance of Aboriginal and Torres Strait Islander service delivery, holistic health and cultural safety, but also the importance of community control. The question then becomes how to replicate this in terms of research.

3.2 Panel strategies for safer research practices

During the 2024 Iutruwita / Trouwerner panel discussion, delegates and panellists gave several examples of how research could be conducted in a way that promotes Aboriginal and Torres Strait Islander ways of knowing, being and doing. They also gave suggestions and actions with respect to ongoing research projects and programs, including:

- Ceding more research and programs to Aboriginal and Torres Strait Islander researchers and organisations directly.
- Prioritising upskilling Aboriginal and Torres Strait Islander researchers and students.

Ways to achieve this include

- Creating small grant and project funding streams to help develop early-career and post-graduate student researchers in their career trajectories to increase their competitiveness in larger grant schemes.
- Creating incentives for researchers to learn local histories and develop an understanding of community strengths and priorities *before* engaging in research design.
- Codesigning research funding priorities and evaluation mechanisms with Aboriginal and Torres Strait Islander experts. This includes Elders, community leaders, academics, and drawing on existing expert bodies such as the National Health Leadership Forum and the Lowitja Institute.

These strategies can promote self-determination through foregrounding community control in research. The emphasis on prioritising Aboriginal and Torres Strait Islander researcher training and career development signifies a commitment to building Aboriginal and Torres Strait Islander research leadership more broadly. In the interim, codesigning research

initiatives to ensure research reflects local priorities and benefits the communities involved, is imperative.

3.3 Strategies for better practice and codesign in the literature

There are questions of how we can go about making these shifts. Works of scholarship and policymaking are citing the importance of codesigning projects to deliver the promise of creating an Aboriginal and Torres Strait Islander led research agenda. A recent review produced by the Lowitja Institute (Butler, Anderson, Black, et al, 2025) provides an overview of the common pitfalls of poorly designed and implemented attempts at codesign. These examples and the implications of these pitfalls are summarised below:

3.3.1 Consequences of cursory consultation

- Research strategies deemed 'codesign' but lack equal decision-making power and are thus, in practice, merely consultation.
- Gathering input without sharing authority or responsibility.
- Reinforcing tokenism and maintaining power imbalances.
- Failure to deliver sustainable or effective outcomes for Aboriginal and Torres Strait Islander communities.
- Undermining trust and perpetuating exclusion from genuine policy influence.

3.3.2 Considerations for calling something codesign

- Aboriginal and Torres Strait Islander peoples must be equal partners in decision-making.
- Codesign must go beyond consultation to include shared authority and leadership.
- Non-Indigenous institutions must support, not direct, the process.
- Power must be permanently and structurally shifted to Aboriginal and Torres Strait Islander communities.
- Codesign should be led by Aboriginal and Torres Strait Islander organisations and communities from the beginning.

The authors also give a best practice model of codesign with Aboriginal and Torres Strait Islander communities which are summarised in the section below.

3.3.3 Best practice in codesign requires

- centring Aboriginal and Torres Strait Islander voices in policy and research development.
- upholding ethical responsibilities grounded in justice, equity, and human rights.
- aligning with Australia's commitment under the UN Declaration on the Rights of Indigenous Peoples (UNDRIP).
- facilitating culturally responsive engagement and addressing systemic exclusions.
- ensuring Aboriginal and Torres Strait Islander Peoples lead from the outset.
- embedding Aboriginal and Torres Strait Islander leadership at every stage of the process.
- structurally transferring power to uphold Aboriginal and Torres Strait Islander self-determination and governance.

3.4 Examples of self-determination and partnership in health and ageing research

While no single research project can transform the colonial legacy and institutional limits of the research ecosystem, there remain practical steps and concrete examples of researchers undertaking their work in ways consistent with the best practice guide and panel discussion above. Below we present two such examples drawing on research projects that were partly funded through the AAG Research Trust (the research grant arm of AAG). These examples were chosen to show that beyond any single author, method or subject area, research can be undertaken in ways consistent with the self-determination of Aboriginal and Torres Strait Islander Peoples and communities. Publications detailing methods and results from the two research projects are available, including *Aboriginal community-controlled art centres: Keeping Elders strong and connected. Articulating an ontologically situated, intergenerational model of care* (Mackell et al., 2023) and *Use and access of cultural medicines by First Peoples in Australia: Exploratory national insights and implications for health sovereignty* (Gall et al., 2026).

As detailed in the two publications, both projects were grounded in self-determination and worked to promote Aboriginal and Torres Strait Islander ways of knowing, being and doing. The first Arts Centres project is a qualitative study whose first author is a non-Aboriginal woman; the second is a quantitative study led by an Pakana, Truwulway / Trawoolway and Litamirimina person. Despite these differences in leadership and research approach, both studies were designed and governed in ways that prioritised Aboriginal and Torres Strait Islander leadership, promoted cultural integrity, and geared towards community benefit. In addition, both publications demonstrate the steps the researchers undertook to uphold Aboriginal and Torres Strait Islander self-determination in research.

For example, both publications include an explicit researcher positionality statement, acknowledging the professional, personal, and cultural contexts of those involved in producing the research. This step is one way to promote accountability for how the research is produced and with whom responsibility for its presentation rests. Furthermore, both projects emerged from priorities identified by Aboriginal and Torres Strait Islander professional and community groups, rather than being introduced externally by interested researchers.

The Art Centres study (Mackell et al., 2023) was developed through longstanding relationships between researchers and three Aboriginal community-controlled art centres. Representatives from the participating art centres were part of a team of Aboriginal and non-Aboriginal researchers, who codesigned and oversaw the project. Permission and oversight steps included working with the Boards of the three community centres to ensure co-researchers were familiarised and adapting to the ways of working at each site. Cultural integrity was maintained through relational and reciprocal ways of working, including spending time in community, supporting day-to-day activities, scheduling research around community needs, and extending timelines and resources to ensure Elders' voices and stories were included (beyond that which would satisfy Western research paradigms). Findings and lessons were framed through participant voices and returned to communities through a range of accessible formats, including producing a documentary to champion the work of the art centres more broadly (NARI, 2022).

Gall et al.'s (2026) project in cultural medicines was led by a First Peoples health researcher and governed by a majority First Peoples codesign research group comprising Elders, researchers, and sector representatives. The group held cultural oversight and decision-making authority across all stages of the research, including design, analysis, interpretation, and dissemination of the findings. Cultural integrity was further protected through Indigenous Cultural and Intellectual Property safeguards, Indigenous data governance processes, and extensive cultural safety testing of the survey before it. Findings were translated into policy and system-level actions and shared back with communities through yarning, established networks and peak Aboriginal and Torres Strait Islander health organisations.

The studies share several key features: both were initiated in response to Aboriginal and Torres Strait Islander professional group or community-identified needs; both centred First Peoples knowledge and decision-making, explicitly made positionality statements, prioritised returning findings to communities, and sought to produce outcomes that extended beyond academic publication. While the Art Centres study emphasised relational, place-based, and qualitative approaches grounded in community partnerships and storytelling, the cultural medicines project applied Indigenous quantitative methodologies and formal governance structures, with a stronger focus on Indigenous data sovereignty, Cultural and Intellectual Property protections, and informing policy and health systems change. Despite these different methodological approaches, both studies demonstrate how research can be conducted in ways that uphold self-determination in research, while responding to Aboriginal and Torres Strait Islander community priorities.

3.5 The wider research ecosystem

Major research funding bodies such as the NHMRC and the ARC acknowledge the chain of influences shaping research:

> "Responsibility for the ethical design, review and conduct of human research is exercised at many levels by:
>
> - researchers (and, where relevant, their supervisors)
> - HRECs and others conducting ethics review of research
> - institutions that set up the processes of ethics review, and whose employees, resources and facilities are involved in research
> - funding organisations
> - agencies that set standards
> - governments.
>
> While the integrity of processes of ethics review is critical, individual researchers and the institutions within which they work hold primary responsibility for seeing that their research is ethically acceptable." (NHRMC et al., 2025, p.5)

The statement above makes the connections from the individual to the broader systems of research funding and governance for ensuring research is conducted ethically, but we need to think beyond research ethics committees and question who do we reward and how do we define and recognise high quality, ethical research? These questions extend beyond individual researchers and implicate the bodies awarding grants and structuring review processes. This is because these bodies have substantial sway in determining what is

deemed to be a valuable research output, what counts as leadership, and what should be rewarded when assessing grant applications.

NHMRC is shifting to ask all grant applicants to address how their research benefits Aboriginal and Torres Strait Islander health and supports the Closing the Gap targets. This new question, alongside existing Indigenous Research Excellence Criteria, aims to ensure all proposed research considers and contributes to health equity for Aboriginal and Torres Strait Islander Peoples (NHMRC, 2024). While this is an admirable aim, the question continues the framing whereby research and policy interests are 'fixing' Aboriginal and Torres Strait Islander 'deficits' in health outcomes. Thus, it perpetuates narratives of Aboriginal and Torres Strait Islander failings while obscuring the function of institutional and structural racism which underpins many health inequities.

While acknowledging this considerable failing is imperative, deficit discourses have been criticised for potentially "exacerbating Aboriginal disadvantage through the production of evidence that focuses on 'fixing what is wrong' with Aboriginal [and Torres Strait Islander] Australians, and perhaps more problematically, the subsequent internalising of deficit narratives of self among Aboriginal [and Torres Strait Islander] Australians" (Bullen et al., 2023, p.3; see also Fogarty, et al., 2018). Despite the intention to improve health outcomes for Aboriginal and Torres Strait Islander Peoples, greater harm is possible because of these 'deficit' framings. This is especially important to note for Elders and Older Aboriginal and Torres Strait Islander people whose ageing trajectories have been shaped through periods of Australian policymaking characterised by significant discrimination and racism.

It is also important to acknowledge that the NHMRC (2023) both introduced and subsequently updated the Indigenous Research Excellence Criteria based on recommendations from the Principal Committee Indigenous Caucus (PCIC). The criteria were introduced to incorporate and promote support for Aboriginal and Torres Strait Islander health research and/or capacity and capability building; aspirations aligned with the Iutruwita / Trouwerner panel recommendations. The criteria include requirements that an applicant's research proposal

> "…demonstrates how the research and potential outcomes are a priority for Aboriginal and Torres Strait Islander communities with relevant community engagement by individuals, communities and/or organisations in conceptualisation, development and approval, data collection and management, analysis, report writing and dissemination of results." (n.p.)

The introduction of these criteria has accompanied rising engagement with the NHMRC guidelines for ethical research with Aboriginal and Torres Strait Islander health research, but there remains limited engagement with the modes of governance that could enact these principles and ensure partnerships and the principles of community control are authentic (Pickard et al., 2025).

4. Community and control in research

Given the importance of partnership that is promised in the Closing the Gap strategy as well as the NHMRC Indigenous Research Excellence Criteria, it is worth asking ACCOs what their research aspirations and experiences are. As such, we undertook a workshop with community members, Elders, ACCO representatives and other stakeholders at the NSW

Aboriginal Aged Care Forum to gauge the priorities and perspectives in the ACCO sector about research and research partnerships.

The forum was a Booroongen Djugun Proprietary Limited Aboriginal Sector Support and Development initiative held in April 2026 at the Murrook Cultural Centre on Worrimi Country. As part of the AAG workshop session at the forum, we put the following questions to delegates to explore the familiarity, preferences and knowledge gaps about research of forum attendees.

- Is research something that your organisation is interested in? Why/why not?
- Does your organisation currently conduct or partner on any research projects?
- What kinds of research do you think needs to be prioritised in your community or service?
- What are the benefits of being involved in research partnerships?
- What are the risks of being involved in research partnerships?
- What makes it difficult to get or stay involved in research partnerships?
- How do you know when the research partnership is contributing to positive outcomes for your community or service?

During the workshop, participants offered their thoughts through verbal feedback and on post it notes and butchers' paper to be shared with and collated by AAG. From these questions, forum delegates (including local Worimi Elders) identified a desire for strong community governance structures to authorise and oversee research. Delegates also highlighted that tight project timelines and competing expectations risk negative outcomes for community members. Finally, it was made clear that researchers must be trauma aware and healing informed, thereby ready to adapt projects when unforeseen harms or competing community priorities arise. Forum delegates were particularly concerned for Elders and Stolen Generations survivors who have experienced abuse and violence at the hands of non-Indigenous 'experts' and 'caretakers' in their lives. While researchers delivering a project may not intend to trigger or harm community members, their lack of knowledge about the community or a rigidity about delivering a project were cited as risks to communities and barriers to engaging in research partnerships.

4.1 Governance and oversight

Some delegates called for creating governance structures specifically led by Elders to better enable Aboriginal communities to determine which research is undertaken in their community, at what time, and in what manner. Others were concerned about transparency around decision making and community representation in authorising research, emphasising the need for ensuring there is time and appropriate scope for all affected community members to give feedback on proposals.

Forum delegates highlighted that meaningful or equal partnership means that the community members with the appropriate forms of knowledge and authority are positioned as the overseers of research projects, not convenient individuals. For example, as previously highlighted, some forum participants suggested only prominent Elders and community

leaders ought to be the ones to guide engagement with the community, rather than junior service staff members or research students. This goes some way towards working to ensure power imbalances are addressed. As previously mentioned in section *2.4 Power imbalances in research structures*, it is often the community members who are left to address the fallout from research projects that go awry. Hence the suggestion that Elders and community leaders who hold the knowledge and authority to make these decisions helps mitigate the risk of harms and create a more equal decision-making structure.

It was agreed that implementing effective governance structures with the right community representation prior to setting a research agenda is imperative to ensure all parties involved in the research project can address their aspirations and needs. To do this requires respect and understanding for local cultural protocols, traditions and customs. Researchers should be prepared to be led by community, not vice versa. Some forum delegates highlighted that mainstream governance structures did not comply with local protocols. For example, failing to comprehend the importance of men's and women's business and roles in their communities meant that there were incomplete permissions being sought because the lines of authority and decision-making were not appropriately accounted for. Thus, emphasising not only the importance of governance and oversight in general, but the importance of knowing the decision-making protocols that are specific to a community.

4.2 Project timelines, competing expectations

The need to allow adequate time across the lifespan of the research project was raised repeatedly by forum delegates. This includes meaningful engagement, relationship-building and establishing trust prior to the research agenda being set. Delegates agreed that these processes cannot be rushed, and yet are often not undertaken before project funding is secured, or a research area is determined. This means that community representatives felt they were unable to shape the priorities, timing and outcomes of the research project at the initial proposal phase.

In addition, inadequate timelines can compound the risk of negative outcomes. For example, focusing on completing a research project because of funding or reporting timelines was said to risk community needs being sidelined. Forum delegates talked about experiences where community timing was seen as a preference rather than a fundamental requirement, while reporting or funding timelines were treated as non-negotiable. Thus, the time allotted to undertaking the research can both reveal or create competing priorities in the project. The treatment of these competing priorities comes back to mainstream approaches sidelining Aboriginal and Torres Strait Islander ways of being, knowing and doing. Often this comes to the fore when the funding body requirements are seen as a higher priority, or more legitimate consideration, than that which is being advocated by community. Delegates noted that under these circumstances, it is generally the community priorities that are neglected in order to honour funding body requirements, making entering into research partnerships risky.

4.3 Trauma aware project design

Furthermore, research positioned as trauma-aware and healing informed must demonstrate practically how the project can be adapted, paused or even abandoned in times of Sorry Business, crisis, competing priorities and community needs. Forum delegates explained that Elders and Older Aboriginal and Torres Strait Islander people in particular bear a lot of

responsibility and can carry a lot of cumulative grief. At times, the research may need to pause or pivot to ensure the wellbeing of the advisors overseeing the project or the wider community involved. A research project is not contributing to good outcomes if Elders and Older Aboriginal and Torres Strait Islander people are being stressed, alienated or burdened in the name of delivering the outcomes.

4.4 Returning knowledge to community

Finally, forum delegates made it clear that the knowledge and information generated by the community must come back to the community and participants. This is a part of the commitment to reciprocity and transparency which are pillars of ethical research as outlined in the 2005 NHMRC guide. Forum delegates wanted resources and time to be set aside to ensure that researchers share back their findings in accessible, culturally appropriate ways. Research cannot benefit a community if the community does not know what came of it.

As discussed in section 3.4, there are a range of ways findings and learnings can be shared back with participating and partner communities. These may include events, yarning sessions, translated materials and mixed media outputs. Merely publishing a paper in a peer-reviewed or professional publication is not enough to ensure those whose contribution underpin the research can also share in the learnings of what the research identified. A good example of producing alternative content for community comes from the first Interim First Nations Commissioner, Andrea Kelly, whose Community Report (Department of Health, Disability and Ageing, 2024) was made specifically for people who would not be reading the official report, but who were implicated in the findings and recommendations. Furthermore, the Community Report resource and the official report were distributed through a number of community and national networks to ensure broader reach.

4.5 Summary of workshop

While this is not an exhaustive nor comprehensive assessment of ACCO perspectives of the research landscape, it is illustrative of the kinds of considerations ACCOs weigh when entering research partnerships. This means that mainstream research must have greater curiosity about the experiences and knowledge systems of Aboriginal and Torres Strait Islander Peoples in general, but especially when considering undertaking research in Aboriginal and Torres Strait Islander communities.

Forum delegates made clear there were a number of practical steps that must be undertaken to ensure community aspirations are central, that research agendas and projects are shaped through the lens of the communities they are said to be representing, and the dialogue across research traditions and knowledges are on equal terms. The requirements of appropriate governance and oversight, sufficient time and being trauma aware and responsive, as well as bringing the findings of the research back to community, are practical ways researchers can align with the 2005 NHMRC guide and demonstrate a genuine commitment to codesign.

5. Recommendation summary

Overall, there was a striking amount of consistency across the panel recommendations, the Lowitja Institute's review of best practices in codesign (Butler, Anderson & Black, et al.,

2025), and the forum recommendations from community-controlled organisation representatives. These recommendations included but are not limited to:

- Aboriginal and Torres Strait Islander researchers and organisations must be able to shape the research agenda and policy programs from the start (not after the idea or priorities have been set).
- At the same time, education and research institutions need to develop pathways and supports for Aboriginal and Torres Strait Islander researchers and students. Practical strategies such as small grant and pilot project funding streams aimed at developing early career and post graduate student researchers, helping them be competitive in larger grant schemes.
- Incentivise and reward researchers learning local histories and developing lasting community relationships (i.e., building partnership and engagement resources into grant applications and funding awards).
- Centring Aboriginal and Torres Strait Islander voices in policy and research development, such as codesigning research funding priorities and evaluation mechanisms with Aboriginal and Torres Strait Islander experts.
- Embedding Aboriginal and Torres Strait Islander leadership at every stage of the process, including determining the ways programs and policies are evaluated.
- Structurally transferring power to uphold Aboriginal and Torres Strait Islander self-determination and governance (e.g., through supporting the development of Elders or project governance groups).

6. Conclusion

Research ecosystems need to be conducive to Aboriginal and Torres Strait Islander values, ways of working and priorities. Currently, rather than being at the centre of research strategies, Aboriginal and Torres Strait Islander research is deemed to be something that can be done within the current system. This does not align with the promise of the National Agreement on Closing the Gap strategy to transform government institutions, nor does it align with the responsibilities outlined under the UNDRIP, requiring Australian institutions to recognise Aboriginal and Torres Strait Islander self-determination, as well as cultural distinctiveness. Thus, even though individual researchers and teams are committed to promoting Aboriginal and Torres Strait Islander led, strengths-based research attuned to the colonial contexts of their respective research projects, without recognition and change in the highest levels of the research ecosystem, these competing frameworks will continue to create undue burden on staff, force tight timelines and unrealistic expectations into research projects, and ultimately fail to translate into meaningful change on the ground.

Across the panel discussion, in the literature on codesign and at the aged care forum, there was consistency around aspects of research that need to change or be included in research design and completion so that Aboriginal and Torres Strait Islander ways of knowing, being and doing might stand on equal footing with Western research paradigms. The first is the primacy of forming relationships and trust before undertaking research. This means communities, through a governance or engagement forum, are in a decision-making role before project funding is sought or a problem identified. Secondly, project timelines must be both realistic and adaptable. They should account for the fact that communities may need to prioritise other commitments at different times and therefore require flexibility. Research

initiatives must also be designed to respond effectively to changing circumstances. Thirdly, the priorities of funding bodies, research institutions, and the broader research ecosystem should not take precedence over those of the communities involved. Achieving this requires a fundamental shift in how research is structured and evaluated, placing greater value on community engagement and ensuring that outputs are relevant and beneficial to the communities themselves. This approach must also be appropriately supported through adequate resourcing and professional recognition.

Ultimately, there are two concurrent forms of capacity building that need to be undertaken before Aboriginal and Torres Strait Islander leadership, knowledges and practices are realised in a substantive way, rather than a tokenistic way in Australian research ecosystems. It is essential that Aboriginal and Torres Strait Islander researchers and policymakers have the skills and training to compete with non-Aboriginal and Torres Strait Islander researchers and research institutions. This means resourcing pathways to promote Aboriginal and Torres Strait Islander led research and supporting Aboriginal and Torres Strait Islander researcher career development. Secondly, it means capacity building for the broader mainstream research ecosystem. Public research funding bodies, educational institutions and researchers need to incorporate strengths-based, place-based criteria into assessing and designing research agendas. While it is one thing to ask individual researchers applying for funding to NHMRC how their research benefits Aboriginal and Torres Strait Islander health and supports the Closing the Gap targets, it is another to honour the commitments of the National Agreement on Closing the Gap and the UNDRIP in terms of transforming government and promoting Aboriginal and Torres Strait Islander self-determination in the research and policy ecosystem.

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