Keeping Research on Track? Aboriginal and Torres Strait Islander Accounts of Ethical Conduct in Health and Medical Research

Discussion Paper

Prepared by Felicity Collis *(Gomeroi)* and Michelle Kennedy *(Wiradjuri)*

Acknowledgement

We respectfully acknowledge the Traditional Custodians of the lands, skies, seas and waterways of these geographies and terrains since time immemorial. We acknowledge that this land was never ceded, nor was our sovereignty.

This report was developed on the unceded lands of the Awabakal and Worimi people. We acknowledge the Traditional Owners of Country and pay our respect to them, their culture and their Elders past, present and future. They have paved the way, with strength, resilience and fortitude, for future generations.

ISBN: 978-1-922885-12-8

First published in June 2025

This work is published and disseminated by Lowitja Institute.

This report has been published by Lowitja Institute, working with authors Felicity Collis *(Gomeroi)* and Michelle Kennedy *(Wiradjuri)*.

About Lowitja Institute

Lowitja Institute is Australia's only national Aboriginal and Torres Strait Islander community controlled health research institute, named in honour of its co-patron, the late Dr Lowitja O'Donoghue AC CBE DSG. We work for the health and wellbeing of Australia's Aboriginal and Torres Strait Islander peoples through high-impact quality research, knowledge exchange, and by supporting a new generation of Aboriginal and Torres Strait Islander health researchers. Established in January 2010, Lowitja Institute operates on key principles of Aboriginal and Torres Strait Islander leadership, a broader understanding of health that incorporates wellbeing, and the need for the work to have a clear and positive impact.

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About the artwork

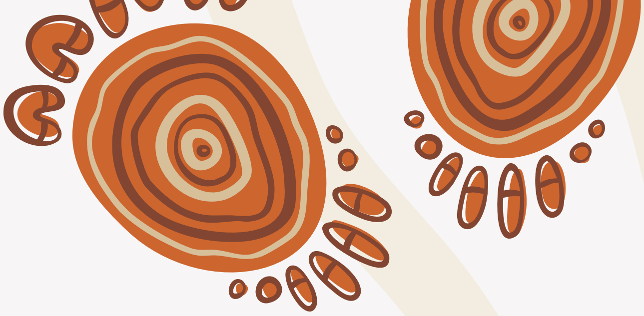
'Connect, Listen and Share Deeply' by proud Wiradjuri Artist Leticia Anne Forbes © Yirra Miya.

This artwork reflects the journey the team at *Murru Minya* went on, to connect deeply, listen deeply, and share deeply. It honours knowledge sharing, experience, and cultural ways from across Country and the importance of First Nations peoples voices.

Throughout the artwork, there are many different community circles of people coming together to sit and yarn to connect and share their voices. These community circles are all different and unique in shape and size to represent that not one community is the same as another; when working from an ethical space, it's important to do things differently and always following the ethics and community-led protocols. The three layers intertwined into each community circle, represent the layers of knowledge shared from different generations of people who are shaping the messages and the leaders in the space.

Mother Earth is honoured in this piece to reflect the journey taken across Country to gather insights and voices. There are many journey lines surrounding the different beautiful and diverse landscapes from our skies (top right), to waters (rivers – top right and bottom right and ocean – centre left), to land (bottom right) and desert (middle sand) and creations (animal tracks). The kangaroo and emu tracks are used to represent the moving of always going foward.

In the centre is an important element that represents continued connection and accountability. It reflects spreading the knowledge onwards through the connected communities and journey tracks. It also reflects the significance of the kinship connections made through the journey of *Murru Minya* and their community responsibilities leading back. It reflects the importance of reciprocal relationships and communication, that what is given should be returned with respect.



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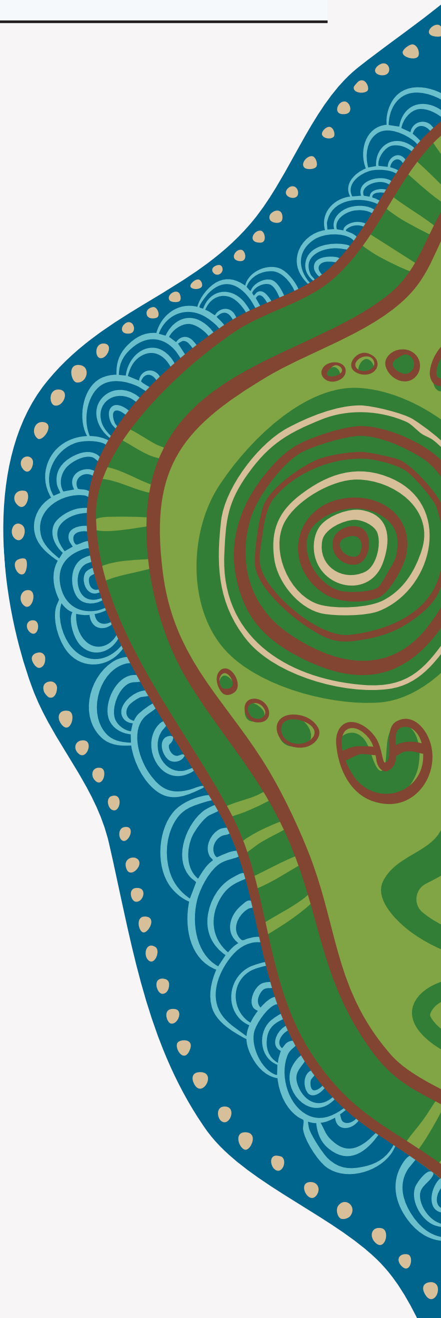
List of abbreviations

Acronym	Definition
ACCHO	Aboriginal community controlled health organisation
AH&MRC	Aboriginal Health and Medical Research Council
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
HREC	Human research ethics committee
NHMRC	National Health and Medical Research Council
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples



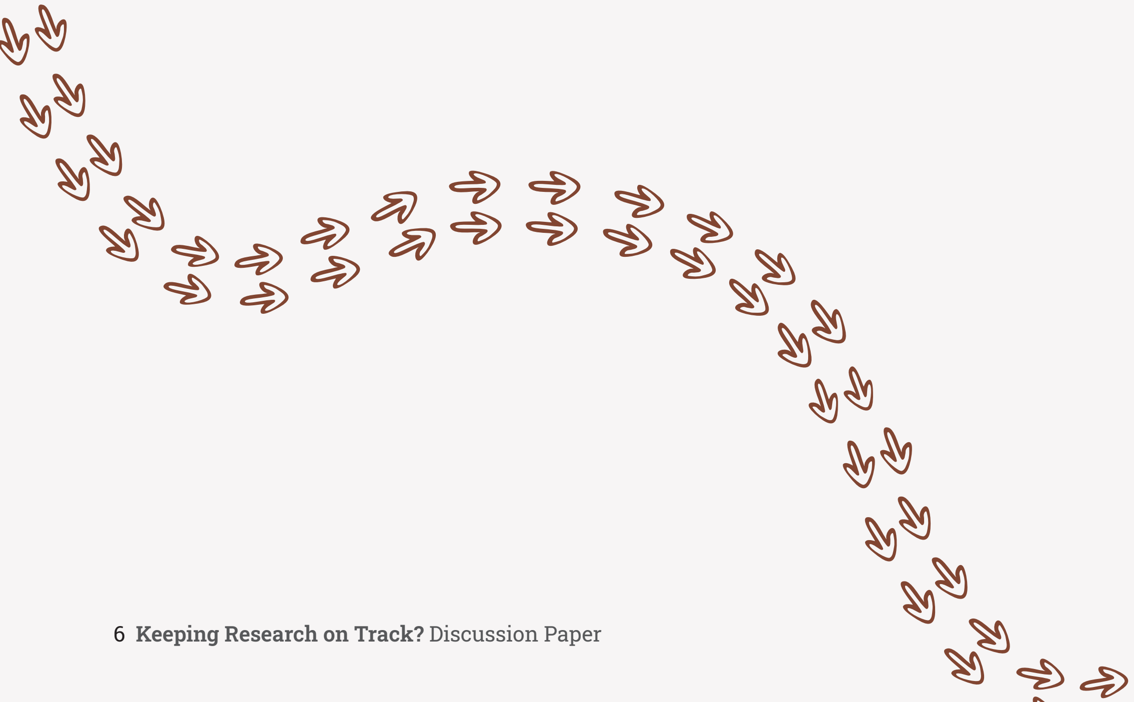
Executive summary

This discussion paper reports on an evaluation of ethical practices and systems in Aboriginal and Torres Strait Islander health and medical research. Led by two Aboriginal women, this work upholds Indigenous methodologies and methods to offer truth-telling and calls to action from Aboriginal communities. We call for improved implementation and conduct of culturally safe and respectul research that truly benefits the health and wellbeing of the First Peoples of this land.

This discussion paper has been prepared for Lowitja Institute in partnership with the Aboriginal communities who have invested their time and expert knowledges to the continual advocacy and collective drive towards improved outcomes for all Aboriginal and Torres Strait Islander peoples. The aim of this project was to privilege Aboriginal and Torres Strait Islander community voices and experiences, and the subsequent impacts of current health and medical research practices.

This work highlights community-led solutions on the ways in which the system of research should be critically transformed to appropriately uphold Aboriginal and Torres Strait Islander rights in research. These findings contribute to a broader body of research examining the implementation of ethical guidelines and practices from the *Murru Minya* project. The *Murru Minya* project has reported key findings elsewhere that complement this discussion by drawing on the collective perspectives of communities, researchers, and ethics committees.

In publishing these sovereign Aboriginal and Torres Strait Islander voices from partnering communities in a Lowitja Institute discussion paper, this discussion paper upholds community rights within the research practices and processes that have been undertaken for this work. In doing so, the Aboriginal communities are the leaders in the authoring and publication of their own stories and knowledges. This ensures their own peer-review processes have been implemented, including the endorsement of the writing and presentation of their stories prior to publication. Aboriginal and Torres Strait Islander leadership and oversight is thus collectively upheld across all aspects of this work.



Introducing Murru Minya

Murru Minya is a national comprehensive examination of conduct across the field of health and medical research with Aboriginal and Torres Strait Islander people and their data, from the perspective of Aboriginal and Torres Strait Islander people. Led by a team of Aboriginal and Torres Strait Islander researchers from across the country and grounded in the voices and rights of Aboriginal and Torres Strait Islander communities, the *Murru Minya* project sought to understand the current landscape of ethical practices and processes in Aboriginal and Torres Strait Islander health and medical research. Born out of the lead Aboriginal researcher's experiences in her own community of unethical research practices, *Murru Minya* is committed to reporting on the work required to uphold Aboriginal and Torres Strait Islander definitions of ethics in health and medical research. This work has been built by and for Aboriginal and Torres Strait Islander communities. It builds on the many influential leaders and communities that have previously laid the groundwork for this project to take place, as well as the work that is simultaneously being led independently by many Aboriginal and Torres Strait Islander communities across the country to ensure their people are protected and safeguarded in research. This work embodies self-determination and sovereignty in action, and establishes a position for which the sector, and its associated systems, must acknowledge to meaningfully reflect on their own positions and power in order to transform into the future. *Murru Minya* is governed by the National Indigenous Health Leadership Alliance (formerly the National Health Leadership Forum) who has provided leadership, guidance and oversight to ensure outcomes from this study are meaningful and actionable for Aboriginal and Torres Strait Islander communities nationally.

Our ethics

The journey of this work has been carefully and intentionally implemented acknowledging Aboriginal and Torres Strait Islander rights to freely determine what, how, when, where and why research is conducted. That is - our ethics, and the processes that follow, are responsive to our collective ways of doing business as Aboriginal researchers and partnering communities. The collective knowledges and wisdom gathered and presented here do not aim to conform to Euro-Western research dynamics; rather, it is situated and responsive to the work itself and the communities that have partnered alongside. By grounding this work in relationality and respect, this work challenges Euro-Western research paradigms of knowledge production. Indigenous ways of knowing, thus prioritise relational ethics that have transcended across time and place. The knowledges and stories here do not conform to hierarchical structures and systems of knowledge. Rather, it is a living entity that is continuously nurtured and carried forward through connection to Country and each other. These lived ethics guide the work through the lived experiences, practices, and realities of the Aboriginal and Torres Strait Islander peoples that are now interconnected in this time and place here.

Access findings from the *Murru Minya* study presented in a *Medical Journal of Australia* supplement here:

Kennedy M, Collis F, Booth K, et al. 'Murru Minya: examining ethical research processes and practices in Aboriginal and Torres Strait Islander health and medical research'. *Med J Aust 2025:* 222 (2 Suppl): S1-S56

And community story here:

Murru Minya 2025, *Our Story – Research Findings* (see References)

Overview

This paper begins with a brief overview of the history of research involving Aboriginal and Torres Strait Islander peoples and then moves to the current context and landscape of ethics in health and medical research with communities today. The intersection of mechanisms enacted within current research systems and processes is highlighted as it pertains to Aboriginal and Torres Strait Islander health and medical research.

Outcomes of this evaluation led by Aboriginal and Torres Strait Islander community members are centred to highlight the action required to transform current research systems and processes. Collective stories and community profiles are presented to privilege and ground Aboriginal communities and voices in this evaluation of current ethical research processes and practices.

Context

Aboriginal and Torres Strait Islander peoples and communities have long been the subjects of research, entrenched in a legacy of coloniality and unethical research practices. Since first contact, Euro-Western research practices have caused significant harm, erasure, and destruction to Aboriginal and Torres Strait Islander peoples knowledges and knowledge systems.

Despite these attempts, Aboriginal and Torres Strait Islander peoples have protected and safeguarded their knowledges, and systems of knowledge production and sharing for thousands of years through close interaction, relationality and caretaking of their Country, kin, and spirit.

Advocacy and self-determination

The *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP) states that Indigenous peoples have the right to self-determination, including the rights to self-governance over the matters relating to them. In Australia, there is a significant history of Aboriginal and Torres Strait Islander people advocating for their rights to health and healthcare. Since the establishment of the first Aboriginal Medical Service in 1971, Aboriginal and Torres Strait Islander communities have continued to resist inequitable access, lack of cohesive public policy, and failure of state and federal governments to provide sufficient resources and services to Aboriginal and Torres Strait Islander people across the country. In 1989, the *National Aboriginal Health Strategy* defined community control as *"the local community having control of issues that directly affect their community. Implicit in this definition is the clear statement that Aboriginal people must determine and control the pace, shape and manner of change and decision-making at local, regional and national levels"*. In the pursuit of social justice and equitable outcomes, Aboriginal and Torres Strait Islander peoples and communities have continued to champion their rights to commnity control of health and health research that involves or affects them.

Dirty research

Aboriginal and Torres Strait Islander people have been researchers and scientists since time immemorial. Since colonisation, Aboriginal and Torres Strait Islander people have long been the subjects of research and investigation, built upon Euro-Western white superiority and deficit assumptions. Health and medical research historically on Aboriginal and Torres Strait Islander people were used as a tool to classify, extract and dehumanise Aboriginal and Torres Strait Islander people to document the 'dying race'. Benefits of these research processes and practices were attributed to the 'white researcher', the 'saviour', with little safeguarding for Aboriginal and Torres Strait Islander peoples' fundamental rights within research systems and to have benefit from the research they were the subjects of.

Examples of these unethical research practice include the disruption of cultural practices and buried remains, measuring of skulls with mill seeds and taking blood samples without consent.

Relevant reading

Bainbridge, R., Tsey, K., McCalman, J., Kinchin, I., Saunders, V., Lui, F.W., et al. 2015, 'No one's discussing the elephant in the room: contemplating questions of research impact and benefit in Aboriginal and Torres Strait Islander Australian health research'. *BMC Public Health*, vol.15, no.1: 1-10.

Humphery, K. 2001, 'Dirty questions: Indigenous health and 'Western research'. *Australian and New Zealand Journal of Public Health*, vol.25, no.3: 197-202.

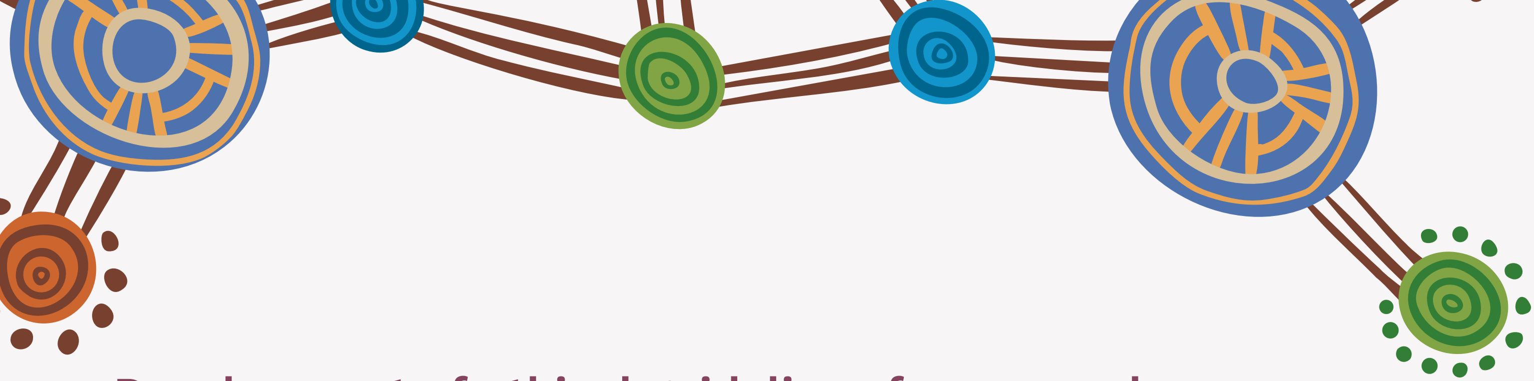
Indigenous scholars globally have highlighted that unethical research practices that privilege Euro-Western knowledge systems are in conflict with Indigenous ways of knowing, being and doing. For Aboriginal and Torres Strait Islander people, research practices and processes have embedded significant mistrust of research and researchers. Tuhiwai Smith noted the word 'research' is 'one of the dirtiest words in the Indigenous world's vocabulary'. This was further emphasised in the *Researching Right Way* ethics review that highlighted the history and legacy of unethical research practices for Aboriginal and Torres Strait Islander people.

Relevant reading

Smith, L. 1999, *Decolonizing Methodologies: Research and Indigenous Peoples*. London: Zed Books.

Towards research ethics?

Aboriginal and Torres Strait Islander communities have been at the forefront of leading change in the field of health and medical research ethics for the past five decades. Prior to the 1970s, Aboriginal and Torres Strait Islander people remained intentionally removed from the national dialogue regarding how research could and should be conducted ethically within the health and medical research field. Aboriginal and Torres Strait Islander people have continued to advocate for health and medical research to be safe, beneficial, and impactful for their communities. Acknowledging that traditional Indigenous knowledge production as well as Western science have demonstrated that Aboriginal and Torres Strait Islander people have been researchers since time immemorial. Building on this, there have been Aboriginal and Torres Strait Islander leaders in the field who have led the development, refinement and endorsement of ethical principles, values, and guidelines in health and medical research. However, Aboriginal and Torres Strait Islander communities have largely remained locked out of leading and driving their own research. Euro-Western research systems have maintained and upheld non-Indigenous researchers access and ability to continue to monitor, measure, and extract from Aboriginal and Torres Strait Islander peoples and their knowledges.



Development of ethical guidelines for research

Over the past three decades, ethical guidelines have been developed to support all researchers to uphold research ethics. In 1986, Aboriginal and Torres Strait Islander people gathered in Alice Springs and led the first discussion on ethical values and principles for Aboriginal and Torres Strait Islander health and medical research. These discussions, which sought to understand community priorities for research, are continued reinforcement and evidence of Aboriginal and Torres Strait Islander expert understandings of research ethics.

The Alice Springs Conference adopted the following specific recommendations:

- That ethical guidelines for health research involving Aborigines be established.
- That these guidelines be established by a forum of Aboriginal people within six months.
- That this forum uses as a basis for these guidelines a number of specific and general guidelines already in existence, that is, research guidelines of Central Australian Aboriginal Congress.
- That the close relationship between ethical guidelines and criteria for funding of research projects be recognised.
- That the Conference nominate an Aboriginal person to act as Convenor.
- That there be Aboriginal representation on the NHMRC Ethics Committee.

This gathering later informed a follow-up three-day workshop with the National Health and Medical Research Council (NHMRC) and representatives from Aboriginal communities. The workshop aimed to:

1. Develop a set of Ethical Guidelines on research into Aboriginal Health.
2. Identify the mechanisms necessary to establish a nexus between the guidelines and the funding of research into Aboriginal health.

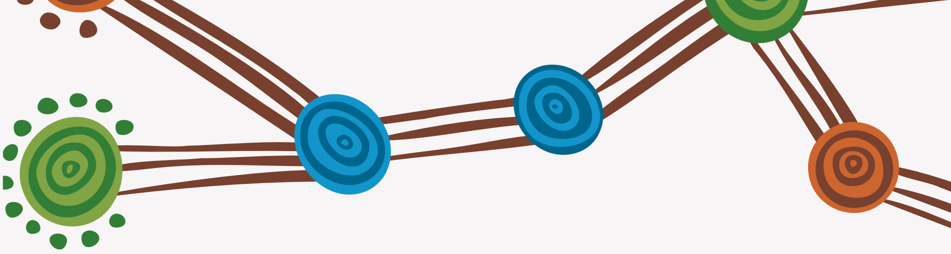
A resulting *Report of the National Workshop on Ethics of Research in Aboriginal Health* laid the foundations for ethical principles, values, and guidelines for health and medical research used today.

These guidelines have continued to evolve over subsequent decades through ongoing Aboriginal and Torres Strait Islander-led review and refinement. For researchers working in the field of Aboriginal and Torres Strait Islander health and medical research, there are a range of local, jurisdictional, and national guidelines required to be upheld that recognise the diversity of Aboriginal and Torres Strait Islander peoples and communities. It is the responsibility of the researcher, through respectful relationship building, to understand what ethical requirements (Western and community-led) must be upheld in the research practice before funding is sought.

NHMRC's *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* states that:

'Ethical research with Aboriginal and Torres Strait Islander Peoples and communities should:

- improve the way all researchers work with Aboriginal and Torres Strait Islander people and their communities
- develop and/or strengthen research capabilities of Aboriginal and Torres Strait Islander people and their communities
- enhance the rights of Aboriginal and Torres Strait Islander Peoples as researchers, research partners, collaborators and participants in research.'



All ethical guidelines are based on the fundamental principles that research must be safe, respectful, responsible, high-quality, and of benefit to Aboriginal and Torres Strait Islander peoples.

Ethics approval

In Australia, Aboriginal and Torres Strait Islander ethical guidelines are upheld via an ethics approval process provided by a human research ethics committee (HREC). HRECs must be registered with the NHMRC, which sets out a number of requirements for the establishment and operation of committees. Currently, NHMRC-registered HRECs across Australia uphold ethics differently by implementing an approach of 'recommended use' of ethical guidelines. In relation to Aboriginal and Torres Strait Islander health and medical research, there are limited specific state-based community controlled ethics committees. There remains a lack of Aboriginal-specific committees across all jurisdictions in Australia. Western Australia, South Australia and New South Wales currently have state-based community controlled committees. Funded by Lowitja Institute, Queensland is currently in the process of determining the feasibility of establishing its own state-based committees, and Victoria has published its Accord and is currently forming their committee.

Funding of Aboriginal and Torres Strait Islander health research

Aboriginal and Torres Strait Islander health and medical research is a multi-million-dollar industry. Between 2014 and 2023, NHMRC was reported to expend >$560 million dollars for Aboriginal and Torres Strait Islander health and medical research. The Medical Research Future Fund has committed >$160 million to the field, both with the vision of improving health inequities among Aboriginal and Torres Strait Islander people.

While Aboriginal and Torres Strait Islander people have welcomed increased investment into improving the lives of Aboriginal and Torres Strait Islander peoples and future generations (acknowledging the continued failure of true advancement in annual Closing the Gap reporting), the impacts of research investment are not always felt on the ground.

It is critical to note that the developmental work undertaken to establish ethical guidelines has called for Aboriginal and Torres Strait Islander community control and monitoring of research funding, which was deemed necessary to uphold research ethics. Currently, Lowitja Institute distributes research funding to Aboriginal and Torres Strait Islander communities, which is not proportional to the national investment. Additionally, some Aboriginal and Torres Strait Islander communities have set regional priorities for governance of research.

Relevant reading

Central Australian Aboriginal Congress, 2021, *A guide for health researchers working with Aboriginal people in central Australia*, Alice Springs, Northern Territory.

Kimberley Aboriginal Health Research Alliance (KAHRA), 2023, *The Kimberley Aboriginal health research model: a handbook guiding research for Aboriginal health and wellbeing*, Broome, Western Australia.

Pilbara Aboriginal Health Research Alliance, 2021, *Principles governing Aboriginal health research in the Pilbara*.

Victorian Aboriginal Community Controlled Health Organisation (VACCHO), 2023, *'Marra ngarrgoo, marra goorri. The Victorian Aboriginal Health, Medical and Wellbeing Research Accord'*, Melbourne, Victoria.

Our approach

Over four years, *Murru Minya* engaged Aboriginal and Torres Strait Islander communities, formally and informally, in ongoing conversations about health and medical research, and how they believe ethics is being upheld, as defined by them. The engagement process between researchers and communities within the project began long before project establishment and funding was granted, and remains an ongoing relationship that is cared for and nurtured between the Aboriginal researchers and communities.

Originating from the lead researcher's observations of the current state of research systems and associated processes—coupled with community reports highlighting disparities between their experiences of research and the reported practices of researchers—this work encompasses both 'formal' research processes in a Euro-Western sense and those continually grounded in, and evolving within, Indigenous research practices and ethics. While there have been some 'recorded' research yarns presented here (to ensure Euro-Western ethics is upheld as is the current requirement), this does not capture the breadth of knowledges that have contributed to this work. Thus, this work transcends the limitations of Euro-Western research and incorporates Indigenous ways of sharing knowledge as critical to how the results and findings of this work have been intentionally presented in this discussion paper.

All Aboriginal and Torres Strait Islander community controlled health organisations were invited to participate in a brief survey examining their processes and position on health and medical research, the importance of ethical principles in research and their recommendations to improve research across the sector.

Fifty-one communities responded to this survey

The survey found that Aboriginal communites want to be involved in all stages of the research process from conception, implementation, and knowledge translation; however, they continue to be approached frequently for a letter of support or during the later stages of the research process when funding and research projects have already been established. Communities reported a significant overburden on their limited resources within current research and funding structures. Aboriginal and Torres Strait Islander peoples and communities echoed and reinforced previous calls for control and power in research.

Read the full community survey results here:

Collis, F., Booth, K., Bryant J, et al. 2025, 'Aboriginal and Torres Strait Islander community experiences and recommendations for health and medical research: a mixed methods study'. *Medical Journal of Australia*, Feb 3, 222, Suppl 2, 6-s15. Accessed from https://pubmed.ncbi.nlm.nih.gov/39893581/

At the end of the survey, community members could opt in to hold a Yarning circle with Aboriginal researchers and community, including Elders and young people.

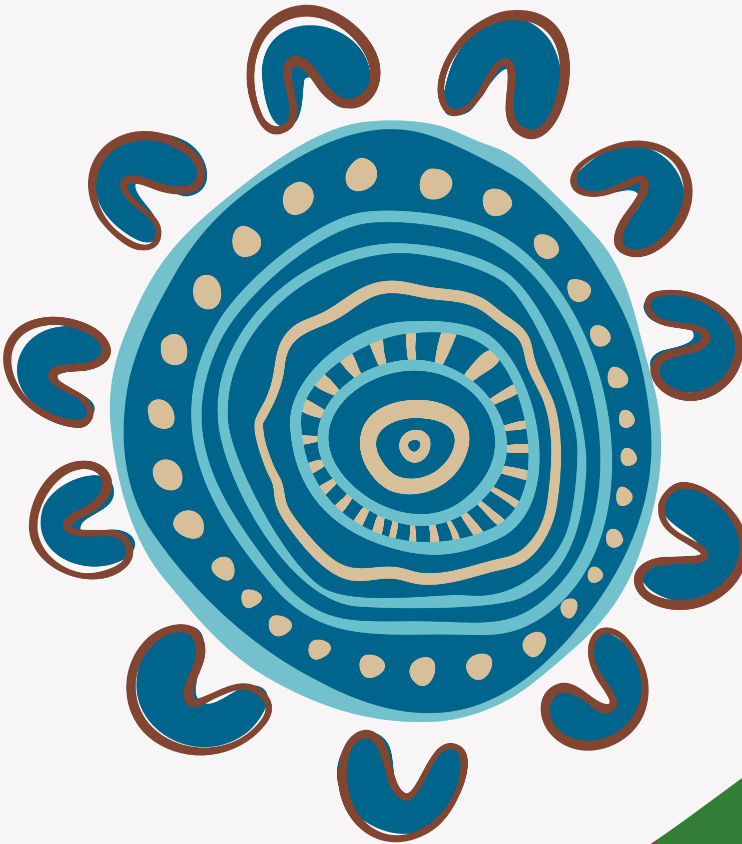
The stories and knowledges presented in this paper provide a basis for how this control and power can be actioned.

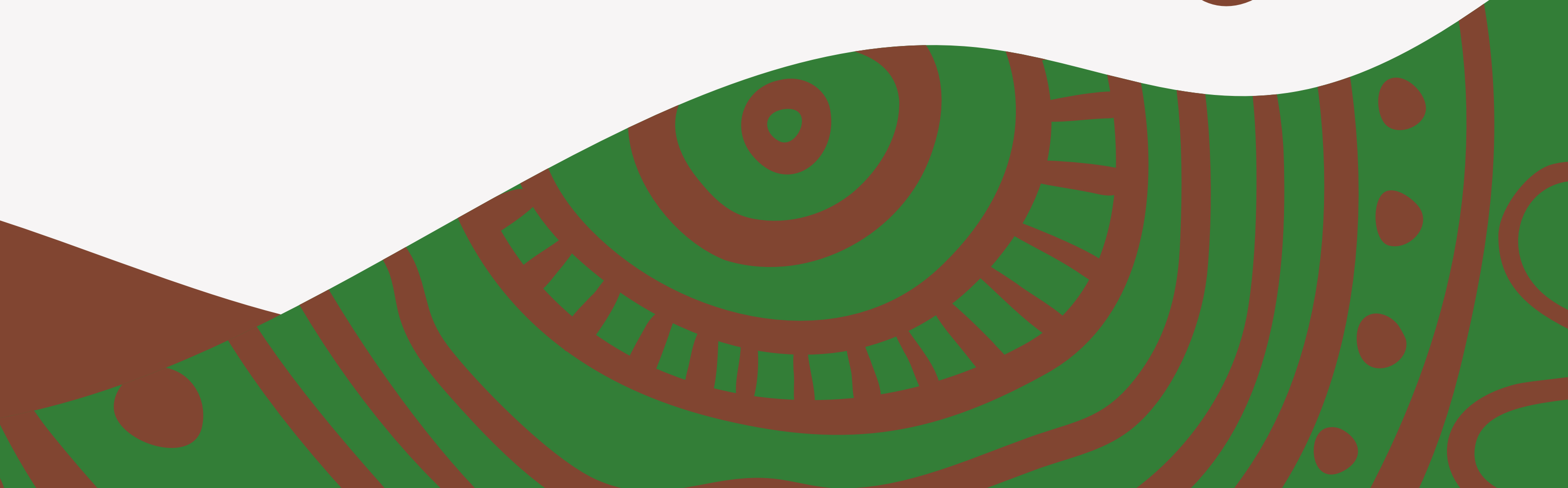
This paper upholds Aboriginal and Torres Strait Islander rights in research and ethics as defined by us. This paper takes a narrative approach which incorporates relevant literature, polices, and guidelines for health and medical research alongside the voices of Aboriginal and Torres Strait Islander people. Three communities identified the desire to present a community profile from their yarning circle and have been the authors, reviewers, and endorsers of their stories for this publication.

This work has been developed in the context of ongoing conversations about how research practices can safeguard and uphold Indigenous ways of knowing, being, and doing to ensure research has real impact in our communities. This discussion paper aims to privilege community voices and experiences to drive calls to action in the field of Aboriginal and Torres Strait Islander health and medical research.

In upholding Aboriginal and Torres Strait Islander rights to governance and decision-making in research practice, the process of conducting yarning circles nationally occurred over an 18-month period. Local consultation and governance processes (including, but not limited to, localised ethical approvals) were followed to ensure communities were respectfully engaged in the planning and implementation of yarning circles in their local contexts.

Yarning circles were conducted by the authors to ensure the safety of the work, community members, and appropriate caretaking of the knowledges that were shared. Our ethics have been embodied and carried throughout this project as pivotal to the safeguarding of communities and their knowledges. This has included careful and considered work alongside communities through a collaborative and iterative process of analysis, sense-making, and ownership of how knowledges would be presented on their terms.

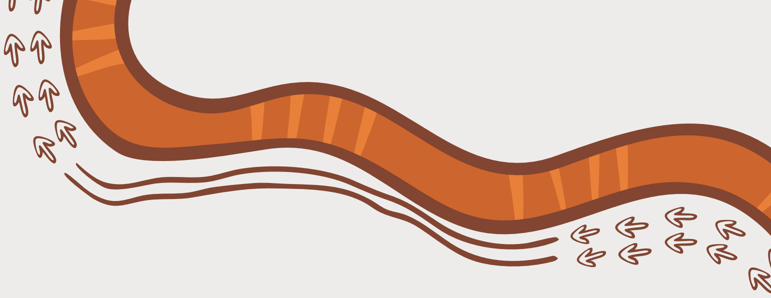




Honouring Country and living knowledges

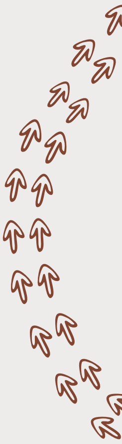
Murru Minya **acknolwedges the unceded lands, seas, skies, and waterways that have been journeyed to across the vast terrains of this country. We acknowledge the collective sovereign knowledges of all Aboriginal and Torres Strait Islander peoples who have generously contributed to an exchange of knowledge.**

We acknowledge that all Aboriginal and Torres Strait Islander people who have engaged in these processes are beneficiaries of the knowledges and knowledge systems that our ancestors have left for us. We acknowledge our responsibilty and will continue to be the guardians of these knowledges - for Aboriginal and Torres Strait Islander peoples have always been the holders, storers, translators and protectors of their stories and knowledges, continually safeguarded within our ways of knowing, being, and doing. These practices serve to reaffirm and continually strengthen our connections to Country, place and kin first and foremost. The knowledges within this discussion paper continue to be owned by the Aboriginal and Torres Strait Islander peoples and communities to whom they originate and belong, and we remain accountable to them. In reporting these knowledges and wisdom with Lowitja Institute, we assert that they will continue to be safeguarded through a continual process of caretaking by and for Aboriginal and Torres Strait Islander people.



Definitions and key terms

This section provides key definitions of essential concepts and terms in relation to Aboriginal and Torres Strait Islander health and medical research. Ethical research practice, to date, is largely defined by the Euro-Western academy – not Indigenous peoples. This work upholds definitions established by Aboriginal communities partnering in this work.



Ethics

Ethics and the concept of ethical practice is not new to Aboriginal and Torres Strait Islander peoples. Communities described their 'ethical compass' as being determined by their lived experience and their relationships with kin and communities, rather than ethical guidelines. Communities spoke about the ways in which ethics should be governed and upheld:

> *'It is our Mob, our people and so, they're my governing bodies. They're my checkers like I know I'm part of this Mob, so if I get this wrong, my names on that, they'll just kill me and run me out of the community. But, no, but for me I think my, what's important to me is that for me my ethics is governed by my Mob.*
>
> *My Mob is my ethics committee.'*

Governance

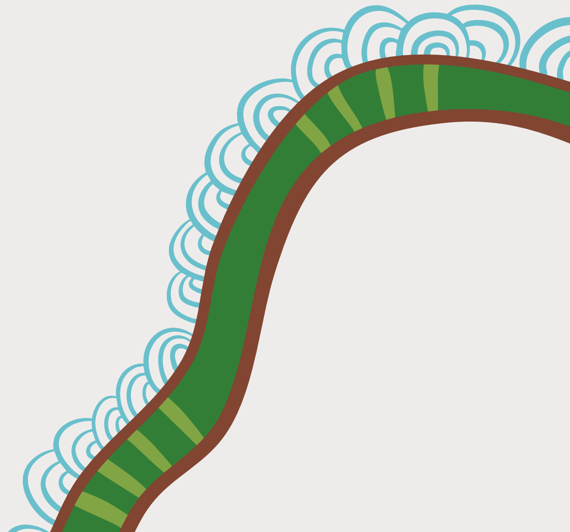
Indigenous governance in research refers to the frameworks and systems that communities develop and implement to guide, oversee, and control research processes and practices:

> *'But what we do in our own communities is that we are working our way now because we know what works. So, if you're not going to come and do it our way, or build up genuine relationships, then we don't really want to know you because you're not going to give us any benefit.'*

Relationality

Relationality underpins the complex, interconnected, and symbiotic nature of relationships between people, communities, and broader contexts for Aboriginal and Torres Strait Islander peoples. It is fluid, responsive and ongoing. Relationality is crucial to ethical Aboriginal and Torres Strait Islander health and medical research:

> *'I think the thing that doesn't get talked about is trust. Why are we signing this form? And what are the implications for us? Like, that form didn't get you to hold the meeting here. It's relationships. It's trust. It's people.'*



Findings

The following sections offer details of community accounts of research and outlines the transformational system change required for research to uphold Aboriginal and Torres Strait Islander definitions of ethics.

This work has been intentionally presented in alignment with current research processes, noting this to be a Euro-Western framework and construct. This was considered and applied to guide the reader in a format that may be able to be taken and critically applied to their own work. We note this paper will be read by non-Indigenous academics, those in leadership roles in institutions and by Aboriginal and Torres Strait Islander people and communities. We write this paper for Aboriginal and Torres Strait Islander people and communities to offer voice and truth telling. We also seek to inform the western academy and colonial systems of knowledge production as they operate today, with the intention of informing new structures and processes into the future.

Across communities, collectively shared values, commitments and compassion for research and the improvement of the lives of our communities remains unwavering. In the spirit of this, and as Aboriginal people both inside and outside the academy, we are inviting you, the reader, to critically reflect and build on your own research practices if you are to apply ethics in an Indigenous way as defined by Aboriginal and Torres Strait Islander people. **Regardless of how the system has been built, the transformation needed will only happen when individuals also begin to take the responsibility and accountability for their part in the system.**

Pre-funding: conceptualisation, development and approval of research

> ‘The consultation or the engagement and relationship building needs to happen way before they decide what their question is before they apply for the funding. They shouldn’t even write the question, the community should write the question.’

Demonstrating respect – is this an oxymoron?

Researchers, working in health, follow guidance set out by the NHMRC to conceptualise, develop and apply for funding to support research activities. The NHMRC defines examples of *‘demonstrating respect’* for Aboriginal and Torres Strait Islander people and communities as *‘ensuring conditions for consent are satisfied for the research and all related activities’.* While NHMRC ethical guidelines outline different stages in which this might occur, there is a distinct lack of responsiveness and accountability to the communities to determine their values and processes for researchers engaging with them respectfully. While national ethical guidance clearly articulates that researchers must demonstrate respect to Aboriginal and Torres Strait Islander peoples and communities, community reports of the ways respect is applied in their experiences of research practice raises questions if actions are respectful at all.

‘Can I have a letter of support?’

Evidence of unethical practices begin right at the conception of a research project and funding submission. Communities reported being bombarded with researchers calling and asking for a letter of support. These calls are not uncommon to occur right at submission deadline, with researchers looking for ways to strengthen their application or only just getting to the point of writing to the Indigenous Research Excellence Criteria. While letters of support are one mechanism for transparency of partnership for funding and ethics applications, these are not always an accurate representation of reciprocal relationships or community-led research. The previous NHMRC Values and Ethics guidelines state, *‘The responsibility for maintaining trust and ethical standards cannot depend solely on rules and guidelines’.* Ethics is an ongoing reciprocal relationship between the researcher and community. Communities reported rarely experiencing reciprocal relationships but rather reported understanding that researchers are building their careers off communities’ work, commitment, and expertise in health and medical research.

Reciprocity and respectful engagement

Reciprocity is an important ethical value and is mentioned 12 times in the NHMRC ethical guidelines. To Aboriginal communities, reciprocity was considered as one of the most important aspects of ethical research. Reciprocity moves beyond the extractive nature of research, and seeks to uphold community priorities and rights by building foundations for community leadership in research, ensuring that the research is beneficial.

All ethical research guidance documents prioritise Aboriginal and Torres Strait Islander consultation and engagement through meaningful and reciprocal relationships, often reiterating the criticality of researchers having responsibility to facilitate Aboriginal and Torres Strait Islander participation throughout all phases of the research as a responsive mechanism to the needs of the community. Communities reported ongoing accounts of unsatisfactory consultation and engagement that was not reflected in research conduct. Often, researchers were seen to be engaging in ‘tick-a-box’ consultation on a singular basis, with little enactment or demonstration of how they were implementing any recommendations made by communities during consultation.

It is possible that current funding opportunities and ethical approval processes at times support unethical practices of engaging with communities. Without clear guidance on what does and does not constitute consultation or engagement, communities report these terms being used as ‘tick-a-box’ exercises to appear ‘culturally appropriate’. As presented in our previous work, some communities report being asked for a letter of support over 100 times per year. Researchers were reported to call, email, and request meetings continually, even when communities have already advised they do not have interest or capacity for the research project. At times communities were told *‘the ethics committee advised we need a letter of support’*. This practice is in breach of ethical guidelines and impacts communities’ experiences in research before the research even commences.

It is critical that research systems that are established to safeguard Aboriginal and Torres Strait Islander peoples and communities acknowledge the need to reduce burden, particularly on our primary healthcare organisations, which do not receive core funding for research in the same way institutions do.

> **‘But also, sometimes they just look at it us as an Aboriginal-controlled organisation, and will say, oh, those guys will give us something. And then we can tick off that we’re culturally inclusive because we’ve gone to an Aboriginal-controlled organisation and we’ve asked them a couple of questions, is usually what happens.’**

Communities also reported that consultation and engagement often occur at the commencement of a project rather than at its conception, meaning that funding has already been awarded and ethical approval obtained. This impacts the ability for community recommendations for implementing their ethics are not always applied to the research. Researchers were noted to invite communities to be a research site, but during ‘consultation’, stated ‘the ethics approval has already been granted for this study so no changes can be made to how the research is conducted’. Communities are then unable to review and inform ethics, including the culturally respectful design and implementation of the research.

Researchers are reportedly unable or unwilling to undertake the administrative processes of amending approved ethics in order to uphold responsive and relational research practices including appropriate participant and community reimbursements, and changes to data measures collected and shared to ensure reciprocal benefit to both researchers and communities.

Applying for funding

The processes undertaken by researchers when applying for funding impacts communities’ experiences of ethical research practices. However, possibly more unethical is that the ways in which the current funding system has been built, which locks out many communities from being able to apply for funding directly to drive their own research.

While Lowitja Institute does fund Aboriginal and Torres Strait Islander community controlled organisations directly to implement research on their own terms, most major funding bodies have established systems that have only considered systems and processes for universities and research institutes to administer Aboriginal and Torres Strait Islander health and medical research.

> ‘Does it have to be attached to academia? So, research is always attached to a university?’

Aboriginal communities are questioning why this system is not changing, acknowledging the limited reported benefit of research and the continuation of unethical research practices.

There has been limited government investment or otherwise in building community controlled research infrastructure. Demonstration of the ethical value of ‘respect’ should acknowledge that communities can and will drive their own research agendas if given the opportunity. While recent grant schemes, such as the Targeted Translation Research Accelerator Round for Indigenous Australian's Living with Diabetes and Cardiovascular Disease, have partnered with Lowitja Institute and successfully funded Aboriginal community controlled health services directly, limited other category one funding bodies have explored how community rights can be upheld through funding structures.

Relevant reading

Lowitja Institute, 2023, *Targeted Translation Research Accelerator Needs Assessment and Prioritisation Project: Discussion Paper*. Melbourne, Victoria.

The continued operationalisation of the current system reinforces unethical practices when communities are unable to lead and direct their own research from implementation through to policy and practice changes.

> 'And I think more funding, we should be able to apply for these research grants but we're not allowed, we're literally not allowed to apply for those research grants and I think that's ridiculous.'

Communities are calling for their own research infrastructure and workforce to be built and calling for funding bodies to redistribute research funding, to ensure sustainability and capacity building within communities.

Communities report needing to build local infrastructure in response to the unethical practices, overburden and constant requests for research. This is an unethical burden placed on Aboriginal and Torres Strait Islander communities without any long term and sustainable funding committed to the establishment and sustainability of structures and systems to uphold ethical research practices.

> **'Or there's no funding anywhere for a workshop run to develop their own research agenda and research staff. And do that thing in terms of training, researchers, employing people to work and do study to get their degrees or whatever. But there's no funding for that. So, how are we supposed to grow our own if we don't have the resources to do that?'**

> **'Where is the career pathway for Blackfellas, or a pathway? Not even a career pathway, a pathway for Blackfellas to get into research and learn about it from scratch, and end up being, with their PhD, with their associate professor, whatever.'**

In spite of the lack of structural reform to the ways researchers and fundings bodies are continuing to be privileged in the current systems of research, communities continue to assert and advocate for their rights in research and adapt to find ways to uphold this. Examples of this include the Kimberley Aboriginal Health Research Alliance, the Pilbara Aboriginal Health Research Alliance, and Central Australian Aboriginal Congress. Each region has developed its own set of guidelines and processes to determine how research will be responsibly conducted as determined and governed by them.

From the desert to the sea: research governance excellence in the Pilbara

Community profile: Pilbara Aboriginal Health Alliance

> *‘We’re a culture that survived. And that resilience that we can walk in our own cultural way in our community and do our stuff our way.’*

Across the Western Desert to the sea, the Pilbara Aboriginal Health Alliance (PAHA) is a partnership formed between three Aboriginal community controlled health organisations, including Mawarnkarra Health Service, Wirraka May Health Service, and Puntukurnu Aboriginal Medical Service. Together, a strong advocacy network was formed to represent the priorities and interests of Aboriginal and Torres Strait Islander peoples living in the Pilbara region.

Pivotal to the work of PAHA is ensuring that health research, and the outcomes of health research, are impactful and beneficial to the Aboriginal communities it advocates for. The establishment of an effective research governance framework has been a groundbreaking achievement that continues to uphold their community rights to leadership and decision-making of the research they are involved with and that impacts them.

> *‘But what we do in our own communities is that we are working our way now because we know what works. So, if you’re not going to come and do it our way, or build up genuine relationships, then we don’t really want to know you because you’re not going to give us any benefit. That’s the strength of this cohort [PAHA], of the four-armed entities. And that shines right through in everything we do.’*

For Aboriginal and Torres Strait Islander peoples, research remains a ‘dirty word’. Previously, researchers have come to the Pilbara wanting to do research that tells a deficit narrative, rather than highlighting the strengths and resilience of the communities as the foundations of all health research undertaken.

> *‘The research hasn’t been done about Aboriginal people, the good side of Aboriginal people, and what they have done.’*

Research approaches that centre local ways of knowing, being, and doing are critical to having good research experiences and impactful outcomes for health and wellbeing. Locally established governance processes and practices ensures PAHA has the oversight and decision-making for research it is involved with and that affects local communities. For PAHA, this includes ensuring researchers are able to build safe and ongoing relationships with the community and board members. In doing so, they are able to collectively challenge Euro-Western research processes that are often in conflict with their local values and ethical ways of working.

> *‘I think another thing is that we are, as Aboriginal people, expected to fit into their construct or other ideas or their western ways of being. We want to challenge that and say, hang on a minute, we’ve survived thousands of years just by telling stories and yarning. We didn’t have to write it all down, like you fellas. So why is this process or this construct more important than the way we do business? Because it was handed down. The storytelling and the cultural way is equally important.’*

The development and implementation of the PAHA governance framework ensures research being conducted in the Pilbara is relevant to local needs and solutions. Optimising health and health research outcomes in the Pilbara remains a driving force to ensure research has benefit throughout the communities within the Pilbara catchment.

> *‘The other thing is, too often information is taken from us and not left with the community or not given back into the community. So, what we want to see is that research is based not only on findings and results or whatever your methodology is. What we want to see is how do we tailor the solution? How do we provide benefit to the community that is being involved in that research?’*

PAHA has importantly highlighted best practice for community governance in health and medical research across the Pilbara region. Community governance is essential for ensuring that Aboriginal communities and peoples have continued and responsive oversight and decision-making within their communities. Community governance upholds the rights of communities to control their own health narratives and knowledge systems, embedding relational approaches that ensure researchers are accountable to the communities. This further strengthens research and research outcomes by effectively engaging in research that is grounded in the needs and values within their local context.

> *‘The word love has to come in. Working together with love to my grave.’*

Ethical approval ≠ to ethical practice

Working within an Aboriginal and Torres Strait Islander ethics framework requires more than a singular review and approval, it requires an ongoing reflective practice and dialogue through relationships with the Aboriginal and Torres Strait Islander community.

A previous Lowitja Institute discussion paper, *Ethics in Aboriginal and Torres Strait Islander health research*, highlighted the complexity of obtaining ethical approvals for Aboriginal and Torres Strait Islander health research. Factors such as the state and territory of the research institution, the availability of a jurisdictional community controlled human research ethics committee, and funding obligations mean there is no straightforward process. Additionally, it was highlighted that current ethics approval processes do not fully uphold key Indigenous values and principles in research, fail to properly incorporate Aboriginal and Torres Strait Islander knowledges and do not ensure adequate representation of Aboriginal and Torres Strait Islander voices as integral to research processes.

Murru Minya's recent review of ethical approvals found a concerning lack of Aboriginal and Torres Strait Islander ethical governance reported in health and medical research. We found that less than half of the research in the field of Aboriginal and Torres Strait Islander health reported obtaining an Aboriginal-specific HREC approval, including a significant number that did not report obtaining Aboriginal-specific ethics approvals in jurisdictions where one operates.

Noting the NHMRC does not currently mandate or specify the requirement for Aboriginal and Torres Strait Islander representation and expertise on ethics committees, our findings highlight that there were a significant high number of ethics committees reported to be approving health and medical research involving Aboriginal and Torres Strait Islander peoples without their oversight or approval. This lack of Aboriginal and Torres Strait Islander oversight and governance of research continues to add risk and burden to Aboriginal and Torres Strait Islander peoples and communities. Without Aboriginal and Torres Strait Islander review for safety, an ethical approval does not qualify research as ethical in practice.

> Aboriginal communities report ongoing unethical research practices, questioning if the obtainment of ethical approval to carry out the research upholds a true practice of ethics.

Ethical approval processes do not always align with Aboriginal and Torres Strait Islander research practices of ethics.

In Australian human research, HRECs operate differently, despite NHMRC outlining a set of Standard Operating Procedures and producing the *National Statement*. There are currently no defined standard operating procedures for HREC-specific review, approval, and monitoring of Aboriginal and Torres Strait Islander health and medical research.

The 1986, the *National Conference on Research Priorities in Aboriginal Health* collectively identified the lack of trust in research and researchers, and that for Aboriginal and Torres Strait Islander people to be protected and safeguarded in research, their values and ethics would need to be centred in the work. Current research systems beyond an ethics committee approval require 'self-regulation' of ethical behaviour, with lack of reporting and monitoring systems for researchers conducting health and medical research.

Hierarchy exists and persists within current systems that does not prioritise Aboriginal and Torres Strait Islander peoples.

Aboriginal communities have highlighted that an ethical approval obtained from an ethics committee does not guarantee that community-based principles and governance are respectfully upheld in health and medical research. Once a single ethical approval has been granted by an institution, reseachers' practice is deemed 'ethical' with no current mechanisms to ensure researchers are accountable to community-based ethical principles and governance ongoing. Community members have asked, *'What ethics is most important? you have national, state and local ethics, but which do researchers have to abide by?'*

Aboriginal communities deem that local level ethics, principles, and practices are critical to the implementation of research that upholds ethics as determined by diverse Aboriginal communities.

Unethical research processes and practices persist in this country today, with research systems in operation that do not uphold ethics as determined by Aboriginal people.

> 'What is the actual place of ethics in Aboriginal research if it's not determined by Aboriginal people? Because how they [non-Indigenous] see the purpose of what ethics is, is different to what we would see?'

Communities reported that localised and small-scale projects are more likely to follow a range of ethical guidelines, principles, and practices, including being foundationally built on local definitions of ethics and practice. However, national studies, often assessed as having higher potential impact, particularly interventions, have been reported by communities to exclude local ethics and practice as defined and directed by them.

While researchers report their adherence to some form of ethical guideline, including Aboriginal and Torres Strait Islander-specific ethical guidelines, this does not mean the research practice has or will uphold ethics as defined by Aboriginal and Torres Strait Islander people.

Recent research from the *Murru Minya* study found that researchers are not consistently implementing all ethical practices outlined in guidelines for research involving Aboriginal and Torres Strait Islander peoples. Further, community reported not always being informed of the approval processes and practices, and they are rarely offered a copy of the ethics committee's approval letter, advised of the ethical approval number, or even shared the comprehensive research protocol for review and comment.

While an ethics committee provides ethical approval to the chief investigator, who is reportedly responsible and accountable to the ethics committee to ensure ethical requirements are upheld, communities report that the chief investigator is rarely the person making direct communication with community members. They are often not the team member travelling to Aboriginal and Torres Strait Islander communities and taking the time to sit with their local governance committees and health service staff to discuss how the research can be conducted safely and respectfully, as defined by their own terms and within their local contexts.

> **'The principal investigator isn't the person sitting in front of you either. So, the actual lead researcher, I know this because they tell me all the time, I got to send their minions out to collect the data. That accountability isn't always there either.'**

Without upholding relational research practice, there are limited mechanisms for a chief investigator to be accountable to the Aboriginal and Torres Strait Islander communities in which they are conducting their research. While a researcher might have an ethical approval as determined by an ethics committee, which may or may not involve Aboriginal and Torres Strait Islander review and approval, research practices will remain unethical when current processes do not uphold accountably, transparency, and responsiveness of Aboriginal and Torres Strait Islander community ethics.

Aboriginal communities reported that Aboriginal and Torres Strait Islander researchers, who uphold relational research practices, also uphold ethics through their relationships and accountability to communities. Aboriginal and Torres Strait Islander researchers are reported to work with partnering community members to develop the research practice in line with local ethics.

‘It is our Mob, our people and so, they’re my governing bodies. They’re my checkers like I know I’m part of this Mob, so if I get this wrong, my name’s on that, they’ll run me out of the community. But, no, but for me I think my, what’s important to me is that for me my ethics is governed by my Mob.’

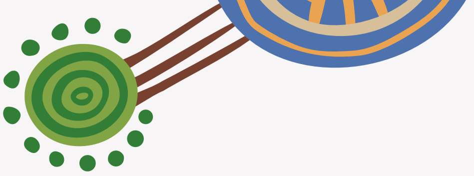
‘My Mob is my ethics committee.’

For Aboriginal and Torres Strait Islander researchers working within the field to be able to uphold their relational research practices, their practices are often required to be in conflict with whitestream ethical approval processes. These restricted and limited ethical approval processes reflect Euro-Western values in administrative approvals, often surpassing the prioritisation of Aboriginal and Torres Strait Islander ethics that ethical guidelines are supposed to promote.

‘So, I feel, why we don’t have many researchers, because we have a dual approval process from Whitefellas, than Blackfellas, then you’ve got to marry the two in between to get it all through. Now, I think I’m going to listen to ideas more so compared to the chair of the University of Melbourne’s Ethics Committee. I don’t know, that’s just how I would feel, because at the end of the day they’ll follow, they deal with day in, day out.’

‘They were rigid by the rules of NHMRC, Aboriginals [unclear] are high risk. But the rules were made for non-Aboriginal people doing research on Aboriginal people. They weren’t made for us doing research on Aboriginal people. And so, the problem is now, and we were the ones who said that was the case, that we wanted that, because people were just going and grabbing stuff and going and doing whatever, so we said that. But now we’re trapped in our own trap, really, because we said we wanted all these things be ticked and whatever for people to do research on us.’

Evidence of the misalignment of ethical review processes and the practice of ethics was shared by Aboriginal communities whereby ethical approval was granted for research practices that did not align with local ethics. Community-based researchers are then employed to implement the research, with the chief investigator not engaging with local community, which resulted in the community-based researcher being accountable to community members for chief investigator researcher and ethics committee decisions. This resulted in significantly fractured relationships for the community-based researcher, for which they have remained accountable for beyond the life of the project.

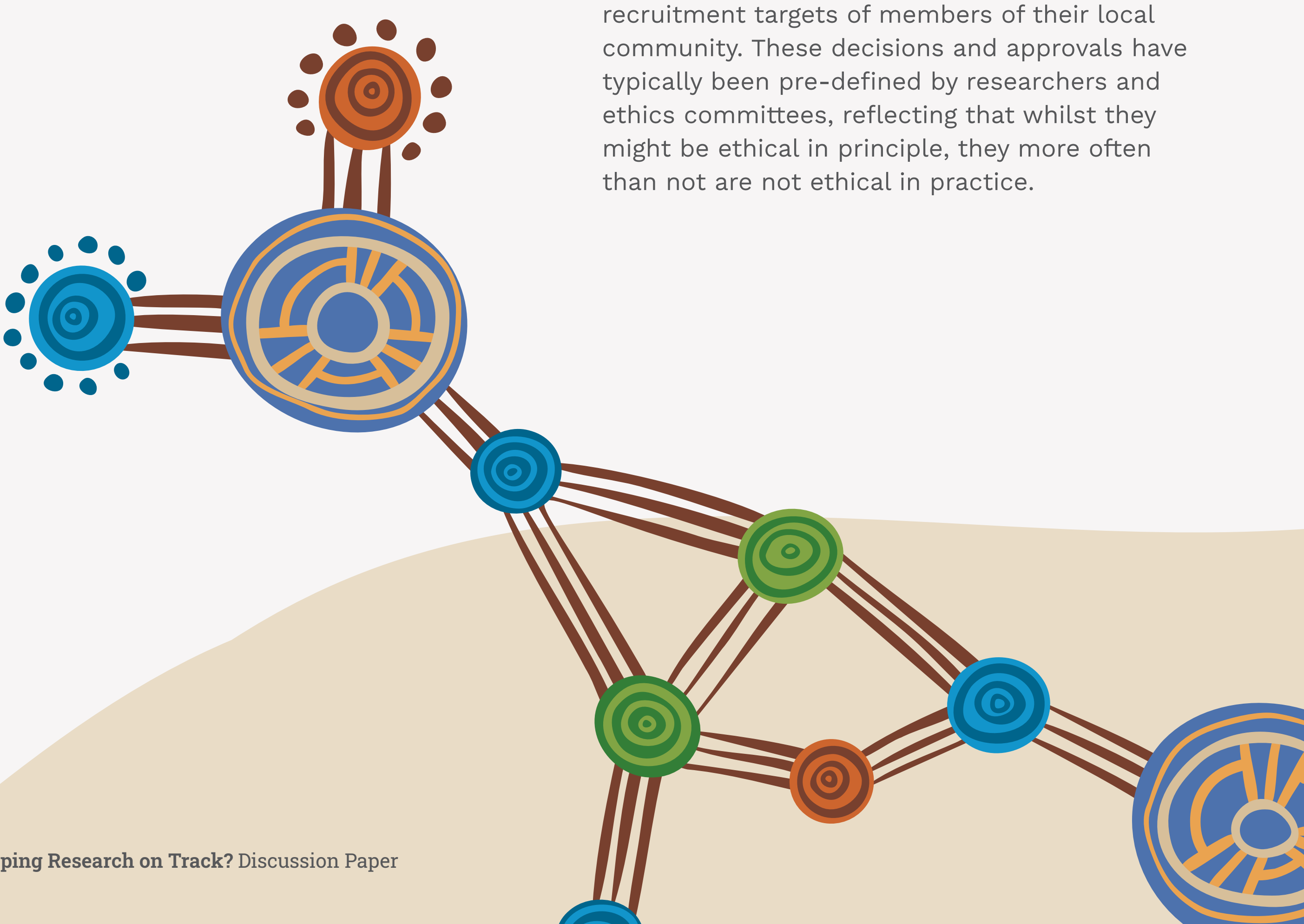


> ‘But somebody in [a city] decided that they would not pay old people. They were only going to pay young people for their information. Even though we were supposed to interview elders and adult community leadership, but no payment for them. And I went, no, we can’t do this. We do not pay children and not pay elders who hold information they’re the… Nobody listened to me. I still get phone calls from one lady in particular from [a remote community] who still accuses me of not paying her. Because I… So, my reputation with that family’s […] in that community. And people don’t get it. They don’t get it. She sees me down the street, she’ll ask me about it. It’s six, seven years ago. My reputation’s […] because of what they did. And the health service wasn’t real strong about telling them, no, you’re not going to do it like this. The protocol already passed by ethics and all. Whoever read the ethics should have known better too.’

Research implementation: data collection, management and analysis

Research implementation is an obvious place for unethical practices to start. As noted above, however, Aboriginal and Torres Strait Islander communities are already at risk of harm due to the processes required to support funding applications and development of ethical approvals. While employment of Aboriginal and Torres Strait Islander people is previously reported as one way researchers uphold ethical research practices, communities have advised this also has potential to generate and influence unethical practices.

Communities reported these experiences to include coercion to sign up to research due to community and kinship ties to the employed research assistant, as well as stress and burden placed on the Aboriginal and Torres Strait Islander staff at a community controlled organisation to meet pre-determined recruitment targets of members of their local community. These decisions and approvals have typically been pre-defined by researchers and ethics committees, reflecting that whilst they might be ethical in principle, they more often than not are not ethical in practice.



‘Our people are always getting researched’: Unethical research practices persist in Yarrabah

GURRINY YEALAMUCKA
HEALTH SERVICE ABORIGINAL CORPORATION

Community profile: Gurriny Yealamucka Health Service Aboriginal Corporation

Gurriny Yealamucka Health Service Aboriginal Corporation is an Aboriginal community controlled health service that has, since 2000, delivered primary healthcare within the Yarrabah Aboriginal Shire, Far North Queensland. Gurriny Yealamucka, meaning ‘good healing’ in the language of the Gunggandji Peoples of Yarrabah, provides culturally safe and holistic care to the local community as Australia’s first community controlled health organisation to deliver primary healthcare services in an Aboriginal community. Grounded in sovereignty and self-determination, and in response to unethical research conducted in Yarrabah, Gurriny Yealamucka has proudly led the development and implementation of its own health research projects to inform current healthcare services and future priorities for the community.

Yarrabah is a distinct Aboriginal community with a history of strength and resistance to colonial control. The community includes Traditional Owners, Stolen Generations Survivors, and those displaced as a result of racialised governmental policies. Community members recounted stories of their parents being ‘kicked out’ and excluded from the community in the 1970s, by the superintendent, for speaking up about unequal pay and advocating for their rights. It was not until the 1980s that control over the lives of Aboriginal and Torres Strait Islander people living in Yarrabah began to change.

Colonial control has laid the foundations for persistent unethical research practices to continue. The community of Yarrabah has a significant history of exploitative and extractive research, including of their cultural knowledges, plants, and even biospecimen samples. Yarrabah community has a living oral and recorded history of researchers coming into the community, extracting, and never returning.

> *‘Researchers coming in and grabbing that information and taking off with it… I’m talking about the papers, who wrote it? It put Yarrabah on the map, and there’s nothing to show for it… He [the researcher] got a new house, he got a new Land Rover, he got everything.’*

While the community is aware that the extractive research practices in Yarrabah have paved career paths and opportunities for researchers, the community believes – regardless of institutions and government having access to the outcomes of research they have been involved in – progress, if at all, has been slow to inform improvements to the health and wellbeing of the community.

The community shared stories about the collection of blood samples and hair strands taken from over 50 community members as children: ***‘I said, why was my blood taken at that time? I couldn’t remember. Well, of course I couldn’t remember. And she said, researchers came to the school, and they took it from the school.’*** Community members reported the impacts of colonial and government control allowed the school’s head mistress to consent on behalf of the children, with their families not being informed and the children not knowing why their samples were being extracted: ***‘I think it was government controlled at the time. And the government superintendent.’***

Stories of how Elders, then children, had their hair strands and blood being taken were reported during a timeframe whereby the National Health and Medical Research Council (1936) and Statement on Human Experimentation (1966) were being established to safeguard participants in health and medical research. Despite these developments, Aboriginal and Torres Strait Islander people, including in Yarrabah, continue to experience extractive and unethical research into present day.

> *‘Do you know our blood in is Canberra? They have my blood!’*

> *‘I don’t even know what they did with that blood, because I haven’t seen them for a while.’*

Yarrabah community reported that in 2016, researchers returned to Yarrabah to obtain consent for continued use and storage of blood samples. One of the researchers who returned has connections to the community which supported a culturally safe engagement process in line with current ethical guidelines for the conduct of Aboriginal and Torres Strait Islander health and medical research.

> *‘About five years ago or six years ago, one lady from Canberra came, she’s a local girl, she came into Yarrabah and said she was catching up on families, on people that bloods were taken in the 60s, and they wanted to check on them. And I said, what for? I said, that should have been over and done with, because from 60s to 2015, or something, that’s nearly 40 years. And I said, what for? That’s should’ve been all finished. And she said, no, we want to follow up on them and see how they go. And I said, no, that’s it. I’m over and done. I walked out. Because our people are always getting research, no matter what.’*

While the process to consult and gain consent aligns with current ethical guidelines and processes, community members reported the process to be confusing and frustrating, with some walking out and not knowing what has happened with their blood samples, nor why researchers were wanting to continue to use them for research. Community members reported not understanding where their blood might be stored and how they could have this returned, if they wanted this now or in the future. Other members recounted being asked to consent on behalf of deceased family members, which was upsetting and confusing.

> *‘I asked, well, what are you going to do with this blood? You’re going to give it back to me, or you’re going to destroy it or what? And she said, “No, we’re going to do research to see how much Aboriginality thing”.’*

> *‘But that day when that young girl had come and asks about the blood and everything, I said, no way. ... I think everybody looked at me with shock, because I just got up and walked out. I said, no way. I said, no, you’re still oppressing us, and went.’*

Nationally, there have been continued efforts by Aboriginal and Torres Strait Islander communities to advocate for rightful ownership and return of their knowledges and bodies. In 2022, the Australian Government supported the return home of 18 First Nations ancestors from Oxford University Museum of Natural History and Pitt Rivers Museum in the United Kingdom to ensure important customary obligations and traditional practices to be undertaken (Australian Government 2022). Within universities, there have been efforts to return blood samples to ensure special burial ceremonies can appropriately take place (Australian National University 2019). Upon reflection about the unethical practices experienced historically and recently, the community is unsure why compensation has never been offered.

‘They should have compensated us’

To be truly ethical, there must be mechanisms of accountability, transparency, and monitoring of researcher practices and behaviours, including ensuring consent processes uphold community rights to respect and self-determination without continued coercion, whereby the community is able to determine its processes and rights around informed consent. Community members shared what appropriate consent processes should look like for them. Informed consent and engagement are not just an administrative or procedural requirement; rather, they are a fundamental practice that continues to safeguard and protect Aboriginal and Torres Strait Islander peoples, their knowledges, and ways of being. Consent processes should transparently discuss the details of the project and the impacts it can have on transforming health and wellbeing outcomes. Alongside this, the community identified that potential participants have the right to say ‘no’ and refuse participation or withdraw at any time. This extended to participants being able to understand this in a range of different ways. Community researchers described one way that the consent process could be conducted that was safe and responsive to their needs:

> *‘If I’m with someone, I will talk through a process with them and say, if you say yes, this might happen. And if you say no, this might happen. But the choice is yours, what you want to do. That’s how I talk to them now.’*

Yarrabah community continues to advocate for its rights, including those to Cultural Intellectual Property that has been extracted by researchers for decades, embedded in the foundation of colonial control. Researchers continue to benefit most from these extractive processes, including being able to author publications and claim knowledges without the ownership and rights to the knowledges they have taken. Community, through its generosity and celebration of their local and expert knowledges, has continually shared these knowledges with researchers, which have not led to any appropriate recognition of them as the knowledge holders and owners.

> *‘Who owns the information when you have researchers coming out? Some university students and they come over here and want to do their thesis maybe on a particular frog or insect in the community. But rather than doing a thesis about a frog, it goes back to them, nothing goes back to the community.’*

The community of Yarrabah are expert researchers and knowledge holders with a deep understanding of ethics in practice. However, they question if researchers know what ethics actually is and how this is applied to them in a responsive and localised way, beyond an ethics approval from a human research ethics committee.

> *‘What would be regarded as a significant one [ethical guidelines and principles]? For me, it’s like honesty. Coming here and listening to the community and what they can do for us in terms of leadership.’*

The community identified that upholding ethical principles, including honesty, should also acknowledge where knowledges have been collected from and consent to how these can be shared. Importantly, it was identified that ownership should always remain with the knowledge holders, and there should be discussions with researchers about who owns and benefits from their knowledges. Yarrabah community was clear in highlighting that its consent to participate in research, and share its data and knowledges, does not change the ownership of their data and knowledges.

> *‘Giving consent for research to happen, for my mind, doesn’t mean giving consent to change ownership of that. You’re still you, this is still your information. This is still the community’s information that they own. They’ve always owned it and they will always own it. Just because a researcher comes in and does research doesn’t mean that that ownership can change hands. The ownership of research should always stay with the ‘subject’, not the person doing the research.’*

Despite the significant and dirty experiences of extractive and unethical research, the community of Yarrabah want to engage with researchers that partner appropriately and develop research that is driven by the community, is responsive to community priorities, and retains ownership within the community to drive community-led solutions. To safeguard future research, the community are leading the development of local governance processes to continually ensure research is done ethically whereby their local and community level ethics and rights, as determined by them, are upheld in any research conducted in their community.

> *‘And we’re going to get more and more people coming into the community doing that [extractive research practices]. Unless we stand up now, we must fight back.’*

‘Informed’ consent

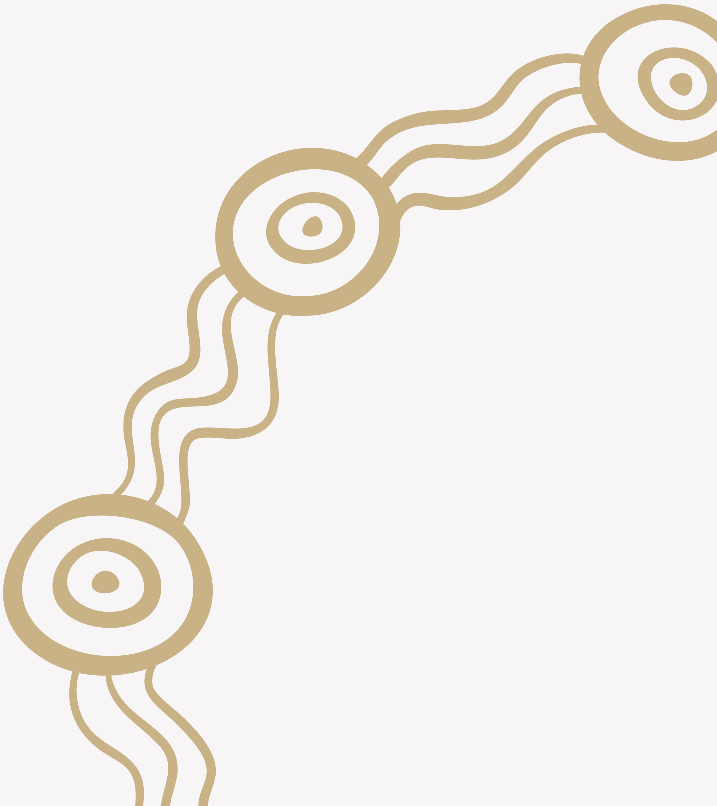
Aboriginal and Torres Strait Islander research assistants who are employed on research projects are most likely to be employed to undertake recruitment and data collection for research projects – sometimes with limited training and support, and rarely engagement with the chief investigator.

> **‘I was working for a large ACCHO out here. I didn’t get any training at all. Not even on how to consent somebody properly. Not even how to use the recording equipment very well. I floundered a little bit in that first field trip, not helped at all by the person that I was working with who would not listen to cultural advice, or pretty much any advice. I ended up crying. I can’t remember the last time I cried in a workplace... But what I realised is people who’ve got university and stuff is, they can’t do the research without people like me, but they don’t always give us the same respect either. And that was very much hierarchical, and Black Folks we’re not hierarchical. It doesn’t sit very well with us.’**

While the ethical requirement of obtaining consent, and in some cases re-consent, is important to ensure participants are informed about the research they are involved in, community members report that unethical practices of coercion continued to be experienced.

Community members report saying ‘yes’ because a research assistant who may have connection to the community is employed to seek consent, or because they felt they *‘had to agree’*.

> **‘I’ve had this happen twice, where I’ve been approached by an Aboriginal research assistant for a non-Indigenous person. And in one case, it was an Aboriginal research assistant collecting data for a non-Indigenous PhD student who had both non-Indigenous supervisors.**
>
> **And I felt really uncomfortable, I didn’t want to take part in the research, but I knew the research assistant really well, and they were really lovely people, and I didn’t want to say no to them. It just put me in such a difficult situation, because I was like, I don’t know want to let this person down, because they’re using all of their relationality to try and get me to be part of the research.**
>
> **And I think really believing that they were doing a good thing, but me seeing that there’s other people who were in the positions of power above the research assistants, as being very problematic. And I was like, I don’t want them analysing my data or I don’t want to be contributing to supporting what they’re doing. And it was really horrible. It was really like sleepless nights horrible.’**



Obtaining informed consent should align with ethics as defined by Aboriginal and Torres Strait Islander peoples and communities, and be foregrounded in relationality. Relationships and trust are required for it to be considered ‘informed consent’ that upholds relational ways of doing and being. Current processes to obtain informed consent is a Euro-Western administrative process, alongside the requirements and approvals of what an ethics committee deems to be safe and appropriate. Often ‘consent’ is being obtained without the chief investigator being present or building a trusting relationship with the community, which is in misalignment to community ways of conducting business.

> **‘I think the thing that doesn’t get talked about is trust.**
>
> **Why are we signing this form? And what are the implications for us?**
>
> **Like, that form didn’t get you to hold the meeting here. It’s relationships. It’s trust. It’s people. You could ask [...], why did you come? [...], why are you here? Or who made you come here, or whatever? I think that’s the unexplainable plain language statement consent form. It gets done in an Aboriginal way, so why does it need a consent form?’**
>
> **‘And I think with how you recruit participants to, that tune. Because in my experience people really rely on their relationality with people, and having a yarn with people about what they’re doing as well. And this sort of like, make a flyer with a QR code, and the person has to contact you that way, it doesn’t really sit very well with people.’**

Data collectors

While ethical guidelines, principles, and values exist, current reports demonstrate that community members are most often engaged in research to take on the role of ‘data collectors’. These roles are often predefined by researchers and focused on the research outputs required – not the incorporation or privileging of community knowledges or developing community-based researchers’ skills and expertise to drive research themselves.

> *‘They sit in the university and send Aboriginal staff out to do their data collection, and they write the paper, and they present. And then at the end of the person’s journey of doing the research project or whatever, and then they get to trot around, well, usually at international conference or at national conference, and they stand up there and they talk. Where’s the indigenous co-presenter? If there are non-Indigenous people, where’s the co-presenter? Why, again, are we used for our knowledge and what we contribute, and yet only be on an advisory group? And then, at the end of it, that’s it. You don’t hear. There’s no... Oh, there was only funding for one person. Then you should have sent your Indigenous person. What? Why are you here talking like this is your knowledge? It’s not your knowledge.’*

Researchers are treating community-based researchers like sales staff. Communities reported they are frequently told what the recruitment target (often pre-defined by researchers only) with limited timeframes or paid days to conduct the work (for example, only being employed one day per week to conduct research activities, and employed other days for clinical work). Community members reported being contacted to be advised that they are failing to meet the recruitment targets set by the researchers. Many community members described the 'stress' and burden of being involved in research because of recruitment targets and processes and timelines imposed on them without adequate resourcing from project funding.

> *'The pressure of it will get to anyone. Because if you're constantly being told, I need to get minimum of 100 people for this trial, and I need to get a minimum of four community consultations, and only four people attend it. If those things happen, I can't control anyone else at the community. And I can't control people coming into the clinic.'*

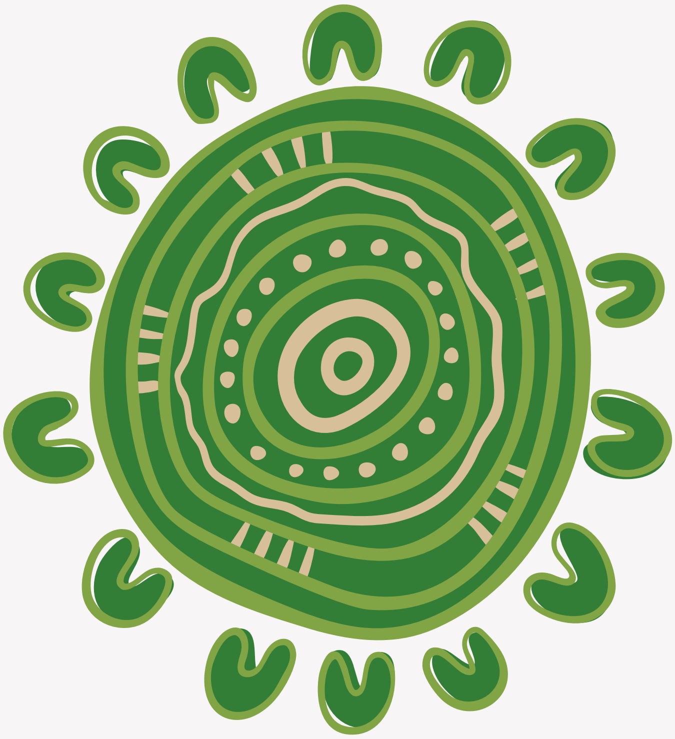
The implementation of randomised control trials within communities presented a number of complexities for the community members employed to implement the project. This afforded little consideration from the research team during the design and development stages of the project of the realities of being a busy health worker, with competing priorities to balance, including providing primary healthcare services to the community. This additional burden and stress of recruitment for the Aboriginal and Torres Strait Islander communities implementing the research causes unnecessary pressure.

> 'Yes, we were responsible for the randomisation. We were responsible to make sure anyone that was new that was starting was updated with all of their training. We were responsible to make sure that they had training with the people that were facilitating the research. But the people doing the research would only come out every three to six months, so that all of their training would have to be online. They'd have to learn about the ears, how it works. And from there, we had to keep registers of who was and wasn't up to date with it. And then it got to the point where people thought that we were the only ones that could do any of the practical stuff for the research, given that everyone was up to date with it.'

Further, lack of reporting and monitoring of ethical approvals does not guarantee researchers will accurately report their data collection methods that affect analysis and interpretation. This lack of transparency is unethical when there is no accountability for researchers to report accurately on their research approaches and outcomes.

> **'And it got written up like this amazing study but basically, they only got information from 15 kids. And so, people will take that and use... That's one of my bugbears about is that people think that it's all the same out here. But [Community A] is so different from [Community B], say, or [Community B's] so different from [Community C] because [Community C's] Catholic.**

I was doing the same study in both communities. I went out every week to [Community C]. Sometimes I stayed overnight, walked around the street in the dark with the kids until two and three o' clock in the morning. In 11 months, not one young person spoke to me. In [Community A], they were lining up to talk to me. The difference because of Catholicism and not Catholicism. And one was a religious set up by the church. Papunya was set up as a blanket station, a ration place. It wasn't even set up as a government. It was just a ration shed.eSo, the differences in people's participation in this kind of thing are incredibly different and very diverse. Most of that information for that study came from just those young people in Papunya, oh, we're going to... Deidentify all that, of course, that to say that you've got some results that speak for young people in Central Australia. Bullshit you do. You don't.'



Knowledge translation: report writing and dissemination

> 'We are researched so much, what is it that shows they are actually listening to that research? That's what I want to know. And where it goes from, from the uni. What do they do with the information? Does it go back to, like if they're, okay let's just say we're doing the breastfeeding, right. We give data from that, it goes to the uni, it goes to other places, but what about the people that that information is about? You know what I mean?
>
> *It needs to have a little bit of ownership and I'm talking community ownership.'*

Knowledge translation is universally accepted as the process of moving generated knowledge from research into real-world application. In Euro-Western research systems, this is often limited to academic pursuits such as research publications and conference presentations. Recent research has noted that *'Knowledge translation is fundamental to making research matter, and critical to ethical research'* and that moves beyond Euro-Western academic metrics in Indigenous contexts. Currently, there are limited mechanisms to ensure the application of research into what is impactful and beneficial for Aboriginal and Torres Strait Islander communities in the field of health and medical research.

There is currently no mechanisms or mandate to ensure researchers return to communities to communicate the outcomes and findings from projects that community members have been participants on or engaged in to implement the project. Community members are frequently ‘promised’ that researchers will return to communities with no way to hold researchers accountable if they do not follow up themselves. Communities are often left without any information regarding the policy and practice changes for the research they participated in.

> *‘Some say, oh, we’ll send you back the feedback and all that sort of stuff.*
>
> *But they give us the feedback but, for me, I don’t get the results, the outcome of the research itself, if that makes sense. They’ve got their big research question, and they ask us for the feedback and what we’ve said, and, oh, is this true and correct? But then I don’t get the result from the big question that they’ve asked. Just what I’ve provided. Yes. The outcome for it all. We just don’t get back.’*

Ethics committees and funding bodies are not monitoring the ethical responsibility of researchers to return to communities, offer community-led knowledges translation, or relational accountability. Communities participating in a previous community survey in *Murru Minya* highlighted that it is important that research findings and outcomes are translated into policy and practice. There are currently no mechanisms to ensure transparent reporting of research approaches and methods occurs beyond ‘taking the researchers word’ in publications and research outputs. Communities rarely report being involved in analysis and dissemination processes for research and receive minimal, if any, details on the broader research question, results, and plan for change. Research might be benefiting the health and medical sector in some way; however, communities are not being directly informed as to how their knowledges, or their data, is driving a solutions approach.

Indigenous and community-led research

Communities have clearly reported in this project that Indigenous and community-led research more closely aligns with Aboriginal and Torres Strait Islander ethics and ways of conducting research. The system must transform to support communities to be funded to lead and direct their own research agendas. Communities have a fundamental right to ensure research is of benefit to them, and, in doing so, they must be able to control and lead their own research.

> ‘If Aboriginal agencies and communities were determining what was needed, then we would be able to develop and create research that is more in line with community needs. Aboriginal voices determining what is needed, done by Aboriginal people, for Aboriginal people, and in line with what is important to us as it will be self-determined.’

Profiling best practice community-led research:

Community profile: Wungening Aboriginal Corporation – Community Ownership Group

Wungening Aboriginal Corporation is a community controlled organisation based in Perth, Western Australia, which has provided culturally safe healing, health, and wellbeing services to Aboriginal people in metropolitan Perth since 1988. Underpinning Wungening's programs and philosophy is the understanding that connectedness is central to healing for all clients it works with. Wungening was established when a group of 40 local Aboriginal people met to discuss their concerns that mainstream services were not responding effectively to the needs of Aboriginal people in the area of alcohol and substance use. 'Wungening' is the Noongar word for 'healing' and reflects the broadening of the organisation's overall purpose and vision throughout the years from delivering drug and alcohol programs to providing a holistic service that addresses the intergenerational trauma that Aboriginal people continue to face across a range of sectors including health, justice, social, and wellbeing issues.

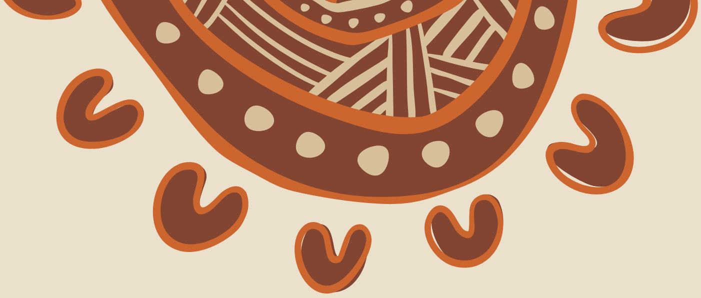
In 2023, the Birdiya Maya Homelessness Research Project was launched as an Aboriginal-led project to provide a public platform for Aboriginal people experiencing homelessness in Perth to tell their stories and identify ways of improving responses to homelessness. The project aimed to identify barriers for Aboriginal people in the greater Perth area in connecting with accommodation and having their needs met, especially in a crisis; and to develop an understanding of the lives of Aboriginal people experiencing homelessness and provide recommendations for future policy change and service delivery.

> *'It was the wisdom, experience, and the skills and the learned experience that we've had as individuals, and even as a group. Once we identified the process of forming the COG. And what that entailed was we needed to have a representative group.'*

> *'...the initial setting up of this group was a very democratic process, because one [unclear] didn't know who was out there, in terms of the elders and the knowledge base, to be able to contribute to the process. And it seemed that there was groups of Elders that were being hand-picked around the metropolitan area for different reasons or different subject areas, but we went through the process of making it very democratic and very community driven. So we identified all the corridors of Perth, and then we ran an electoral process and went out to each of the elders groups in those corridors. So they were considered the drivers of the research.'*

Figure 1: The Birdiya Maya Project Research Approach (Wungening Aboriginal Corporation 2023)

Placing the local Aboriginal community at the centre of the development, implementation and analysis of the Birdiya Maya Project, Wungenging recognised the importance of having Aboriginal-led solutions and for the research to be led by the community. As a result, community members



guided the direction of the research project through extensive engagement from the Elders (the Community Ownership Group), as well as input from research participants. The Community Ownership Group met regularly throughout the project to steer the research, ensuring it was culturally safe and prioritised the diverse voices of Aboriginal people experiencing homelessness across Perth.

> *'So we got the whole range of homelessness and just the lived experience in the room with all of us Elders many of which have come, or I'd say, the majority of us, through living or growing up in overcrowded conditions, living through the experience.'*

> *'And so the story that comes through that is from all of that being facilitated through this group of elders, being led by this group of elders, and documented by the research team, and then handed to the minister and whatever. So it was a great process.'*

Community-led and driven research, deeply grounded in community lived experiences, values, and knowledges empowers communities to self-determine their own affairs. The Community Ownership Group ensured the project remained relevant and respectful to the needs of their local communities, guided by their expertise in community and cultural knowledges. This demonstrates a responsive, best-practice approach to community-led research ensuring communities remain the experts in their own lives and are given the power to lead and direct research on their terms.

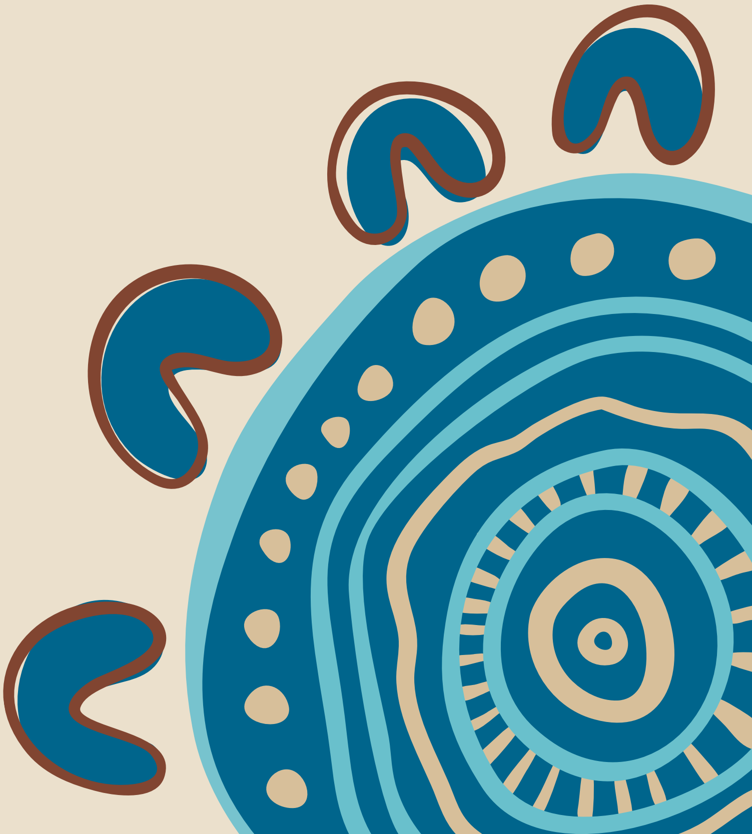
> *'That's the best way to do research, is the lived experience.'*

Read more about the Birdiya Maya Project here:

Wungening Aboriginal Corporation 2023, Birdiya Maya Homelessness Research Project – Community Report, Perth, Western Australia. Accessed from: https://www.wungening.com.au/birdiya-maya-homelessness-research-project

Acknowledging the Community Ownership Group members who generously shared their time and wisdom:

Aunty Roslyn Indich
Aunty Raylene Indich
Aunty Barbara McGillivray
Aunty Beryl Weston
Aunty Bev Port-Louis
Uncle Lenny Yarran
Aunty Lynette Cox
Aunty Vivienne Weird
Aunty Jackie Oakley
Aunty Dot Bagshaw



Indigenous-led research into the future

Transformative and critical action is required

The *National Agreement on Closing the Gap 2020* was built on four Priority Reforms that are driving governments to change the ways in which Aboriginal and Torres Strait Islander people and communities are centred in policy and practices. In 1987, Aboriginal and Torres Strait Islander people called for Indigenous-led systems and structures within research, funding, and ethics. These calls remain relevant to ensure Aboriginal and Torres Strait Islander communities and peoples are safeguarded in research and research systems. There is an urgent and critical need for a systemic overhaul to ensure Aboriginal and Torres Strait Islander health and medical research into the future is responsive to the needs and priorities of Aboriginal and Torres Strait Islander peoples.

In response to unethical research practices and processes being implemented by researchers in the current system, communities are enacting their self-determination in the establishment of systems and processes to protect their communities. This ranges from establishing governance processes for the review and acceptance of the communities involvement in research, to having staff members become the liaison with researchers to determine if the research proposal is in line with community needs and priorities. This role is often in addition to their clinical work. Communities continue to build their own ways of preserving their rights to their data, knowledges, and ways of doing. However, it is critical to recognise that these community systems and processes are being established without funding, community benefit or protection from the breaches of ethical conduct described in this discussion paper.

Communities are upholding their own ways of generating and developing knowledge and knowledge systems in ways that researchers and universities cannot. Communities continue to mobilise and lead the development of their own knowledges despite the current research systems limiting their ability to do so. Aboriginal and Torres Strait Islander researchers and communities inherently understand the systems of ethics required at a local level to build meaningful research within this framework.

> *'I reckon the Western system is starting to just crumble. And I actually think the Western system is looking for solutions to what its system currently can't do. And I think Aboriginal people's way of thinking, doing theme actually has some of those answers. And I think it's actually an atmospheric, structural societal theme, that we're at this crossroads of, the knowledge system that has dominated is actually not working. So, new solutions have to be found.*
>
> *And I actually think there's an opportunity for Aboriginal, Torres Strait Islander people, with their ancient wisdom, with all of the experience of being the oppressed, but still surviving, still having resilience, being able to come up and say, there is a different way of doing it.'*

Key findings and recommendations

Unethical research processes and practices persist within research systems that do not align with Indigenous ethics.

While a range of guidance has been offered to researchers, institutions, and ethics committees for decades, in 2025, communities report that unethical health and medical research practices persist, with Aboriginal and Torres Strait Islander peoples and communities continuing to experience harm caused by research. The breaches of ethical conduct reported here go beyond individual 'unethical researchers' and acknowledge that research operates within an ecosystem void of mechanisms to uphold ethics beyond ethical approvals. Systemic change is critically required. This is best led by Aboriginal and Torres Strait Islander peoples and communities, who are noted in the National Statement and NHMRC Ethical Guidelines to be the beneficiaries of research.

Travelling across the country, community stories about unethical research practices while engaging or being involved in health and medical research encompassed the research life course and ecosystem in which research is currently operationalised.

This paper highlights that decades of implementation, evaluation and refinement of ethical guidelines is not enough to improve the way in which researchers engage with Aboriginal and Torres Strait Islander people and communities. Further, the established Euro-Western processes and standards of ethics are at times in contrast to ethics as defined by Aboriginal and Torres Strait Islander people.

We recommend:

1. Research commissioning agencies conduct an audit and evaluation of Aboriginal and Torres Strait Islander health and medical research funding distributed against ethics as defined by Aboriginal and Torres Strait Islander people.

2. Research commissioning agencies revise reporting templates to embed systematic monitoring processes regarding researchers' adherence to ethics for Aboriginal and Torres Strait Islander health and medical research.

3. Research commissioning agencies, particularly the NHMRC, consider including assessment criteria to demonstrate ethics as defined by Aboriginal and Torres Strait Islander people.

4. That assessment panel composition for all research commissioning incorporates representatives from the Aboriginal and Torres Strait Islander community controlled sector who hold expertise in ethics.

5. That Lowitja Institute be supported to convene a roundtable to inform appropriate community-led systems for health and medical research to uphold researchers' accountability to Aboriginal and Torres Strait Islander peoples and communities.

6. Ethics committees recognise their limitations to approve research for the diverse Aboriginal and Torres Strait Islander people and communities of this country. Ethics committees should establish a process to uphold the rights of Aboriginal and Torres Strait Islander peoples and communities to define place-based ethics for research projects.

7. That an independent, community controlled reporting mechanism is resourced and established by and for Aboriginal and Torres Strait Islander communities to continue to receive and report unethical research practices independent of ethics committees and institutions.

8. That this discussion paper forms the basis for the development of mandatory training on ethics for researchers working in Aboriginal and Torres Strait Islander health and medical research.

9. There is increased research funding directed to the community controlled sector in line with recommendations in 1987 and under Priority Reform 2. Research commissioning should be managed by Aboriginal and Torres Strait Islander community controlled organisations, particularly Lowitja Institute, as a fundamental mechanism to uphold ethics, and Indigenous-led research commissioning process.

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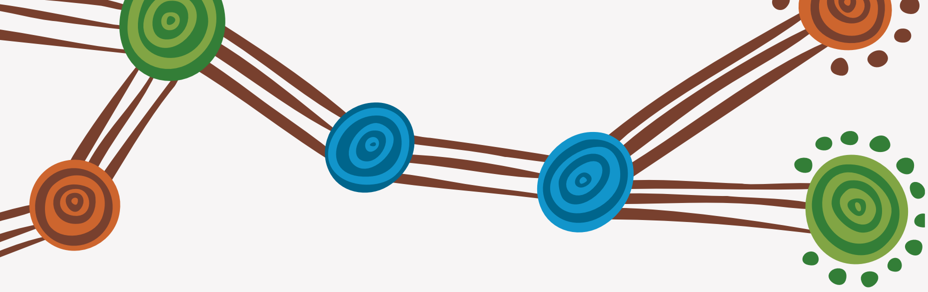

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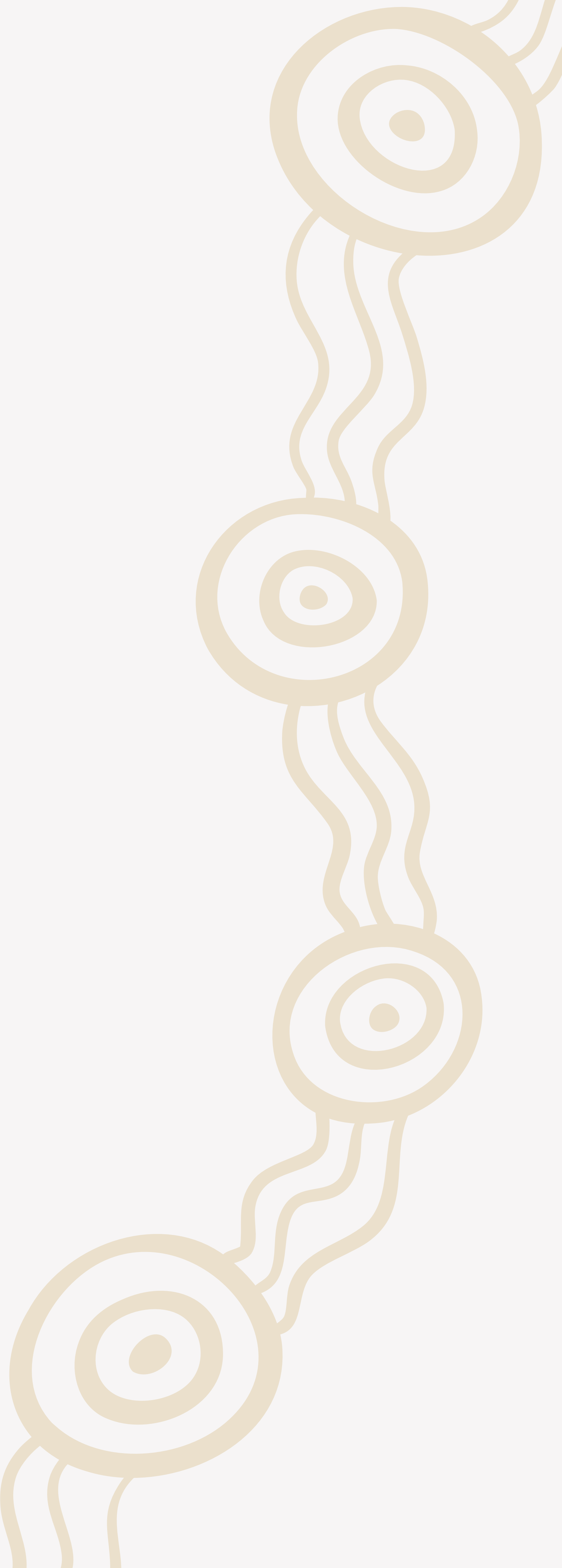

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ABOUT THE LOWITJA INSTITUTE

Lowitja Institute is Australia's only national Aboriginal and Torres Strait Islander community controlled health research institute, named in honour of its co-patron, the late Dr Lowitja O'Donoghue AC CBE DSG. We work for the health and wellbeing of Australia's Aboriginal and Torres Strait Islander peoples through high-impact quality research, knowledge exchange, and by supporting a new generation of Aboriginal and Torres Strait Islander health researchers.

Established in January 2010, Lowitja Institute operates on key principles of Aboriginal and Torres Strait Islander leadership, a broader understanding of health that incorporates wellbeing, and the need for the work to have a clear and positive impact.