LOWITJA INSTITUTE

Ethics in Aboriginal and Torres Strait Islander health research

Discussion paper

Prepared by Associate Professor Michelle Kennedy and Dr Jamie Bryant

Together, we acknowledge the strength of Aboriginal and Torres Strait Islander peoples and the power and resilience that is shared as members of the oldest living culture. We acknowledge all Aboriginal and Torres Strait Islander people and their sovereignty and custodianship over the land, seas and waterways of what is now called Australia.

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.

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This report has been published by the Lowitja Institute, working with authors Associate Professor Michelle Kennedy and Dr Jamie Bryant.

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.

Contact:
LOWITJA INSTITUTE
PO Box 1524, Collingwood
Victoria 3066 AUSTRALIA
E: admin@lowitja.org.au
W: www.lowitja.org.au

Designed by Mazart Communications

About the Artist:
Joley Manton (Foster) is a proud Worimi woman and descendant of the Gamipingal Clan from North Arm Cove, Karuah, NSW.

About the Artwork:
Series – Barray (Country)

Yii Girumbit barray (This is Saltwater Country)

This artwork depicts the Garuwa (Karuah) river which was and remains an integral part of my life and a place where I spent a lot of time growing up.

The Garuwa (Karuah) River is a drowned salt – water barrier river estuary that rises on the south-eastern slopes of Gloucester Tops and flows south reaching its mouth at Karuah (Garuwa). It is located on the western side of Port Stephens, an open tide-dominated drowned-valley estuary.

This river was and remains a source of energy, food, and life for my clan, it was a place where many memories were made with my grandmother and father and will forever be a special place. This is a protected place, a place where I go to sit and just be, a place where I can connect and be guided by them.

The riverbanks are low lying abundant with mangroves, scrub, and woodland natives such as the coastal wattle, snake vine, basket grass and spinifex. The native plants are yellow and green and are represented in this artwork.

Contents

Executive summary	05
Background - The Murru Minya Study	07
Introduction	08
Objectives	08

Key terms and context

Ethics	09
Research ethics	09
Unethical human experiments	09
Declaration of Helsinki	10
National Health and Medical Research Council	10
Statement on Ethical Conduct in Human Research	10
Ethical approval	10
Research governance	11
Aboriginal and Torres Strait Islander research governance	12

Current principles and governance for ethical research in Aboriginal and Torres Strait Islander health

Aboriginal and Torres Strait Islander people's experiences of health research	13
The development of Aboriginal and Torres Strait Islander ethics principles and processes	14
Overview of Aboriginal and Torres Strait Islander ethical principles and guidelines	16
National ethical principles and guidelines for Aboriginal and Torres Strait Islander health research	18
State-based ethical principles and guidelines for Aboriginal and Torres Strait Islander health research	20
Local ethical principles and governance for Aboriginal and Torres Strait Islander health research	22
Aboriginal and Torres Strait Islander specific HRECs and sub-committees in Australia	25

From principles to practice - are Aboriginal and Torres Strait Islander ethical principles being upheld?

Representation of Aboriginal and Torres Strait Islander people on HRECs	31
If we're not on the committees, is there Aboriginal and Torres Strait Islander oversight of Aboriginal and Torres Strait Islander health research?	31
Duplication of ethics approval processes for multi-jurisdictional and national research	32

Where to from here?

Recommendations	35
References	36

List of abbreviations

ACRONYM	DEFINITION
AH&MRC	Aboriginal Health and Medical Research Council
AHREC	Aboriginal human research ethics committee
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
CAHREC	Central Australian Human Research Ethics Committee
HREC	Human research ethics committee
KAHRA	Kimberley Aboriginal Health Research Alliance
NHMRC	National Health and Medical Research Council
SAHMRI	South Australian Health & Medical Research Institute
WAAHEC	Western Australia Aboriginal Health Ethics Committee

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Figure 1	Summary of principles and guidelines that apply to research being conducted with Aboriginal and Torres Strait Islander people in Australia.
Figure 2	Criteria for obtaining approval by jurisdiction.

Executive summary

Ethics approval processes in Aboriginal and Torres Strait Islander health exist to ensure that research involving Aboriginal and Torres Strait Islander people is conducted in an ethical and culturally appropriate manner. However, despite the existence of longstanding guidelines and a national commitment to uphold and promote ethical research involving Aboriginal and Torres Strait Islander people, there remains continued concern that current ethics approval processes do not fully uphold key values and principles, fail to adequately incorporate Aboriginal and Torres Strait Islander perspectives and input, and do not ensure adequate representation of Aboriginal and Torres Strait Islander voices.

This discussion paper was commissioned by Lowitja Institute in the context of ongoing conversations about reform of ethical approval process in Australia to ensure that Aboriginal and Torres Strait Islander health research is conducted to the highest ethical and governance standards, and with the greatest impact on improving health outcomes. Aboriginal and Torres Strait Islander people are the original researchers of this place and have already invested their intellectual thought leadership and direction on what constitutes ethical research conduct. This paper aims to gather this knowledge and leadership, draw on current practice and provide broad recommendations to funding bodies, government, research institutions, academic journals and individuals to uphold Aboriginal and Torres Strait Islander rights to safe and ethical research practice.

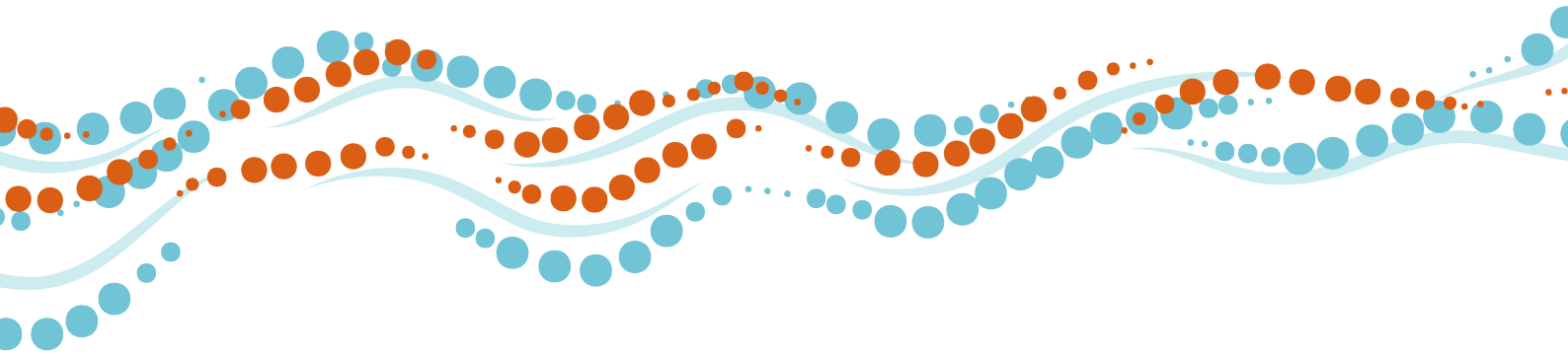
This discussion paper presents key findings from a scoping review of academic and grey literature of research ethics in Aboriginal and Torres Strait Islander health that was guided by the following objectives:

- to provide an overview of current ethics approval and governance processes for Aboriginal and Torres Strait Islander health research in Australia
- to identify key gaps in ethical processes and practices, and areas of reform needed, including the development of a set of recommendations for further advocacy and action.

There are nine key recommendations that follow from this work. Implementing these recommendations will move closer to a research landscape that respects, upholds, and promotes the ethical principles and values that are essential when conducting research involving Aboriginal and Torres Strait Islander people.

1. A National Aboriginal and Torres Strait Islander Ethics Committee was called for in 1987. This should be established to oversee the conduct of national and multi-jurisdictional health research.
2. State-based Aboriginal human research ethics committees (AHRECs) be established in all states and territories. There are still four states and territories where state-based committees do not exist. State based AHRECs should be properly constituted, registered with NHMRC, and located in the Aboriginal and Torres Strait Islander community controlled health sector.
3. Increase infrastructure to support Aboriginal and Torres Strait Islander community controlled Organisations in all states and territories to support the critical functions of all state based AHRECs.
4. All institutions that conduct Aboriginal and Torres Strait Islander health research should facilitate agreement making with state-based Aboriginal and Torres Strait Islander HRECs, ensuring there are systems in place to monitor that research practices reflect Aboriginal and Torres Strait Islander ethical research principles.
5. Nationally consistent guidelines be developed, endorsed and upheld by the NHMRC, institutions and hospitals, clarifying the type of research that requires ethics approval from an AHREC.

6. Nationally endorsed and accredited training in Aboriginal and Torres Strait Islander health research be developed and implemented to build the capacity of the Aboriginal and Torres Strait Islander health research sector including HRECs.
7. That the NHMRC National Statement be updated to reflect that a properly constituted HREC requires at least one committee member to be Aboriginal and/or Torres Strait Islander.
8. In 1987 Aboriginal and Torres Strait Islander people called for ethical publishing practice. Ethical publishing guidelines be developed through consultation and consensus with Aboriginal and Torres Strait Islander people and AHRECs. These guidelines must be upheld by researchers and national and international peer reviewed journals.
9. That NHMRC review and evaluate research commissioning processes. In 1987, Aboriginal and Torres Strait Islander people identified that the most effective way of maintaining appropriate control over the ethical behaviour of researchers and their initiatives was for Aboriginal and Torres Strait Islander community controlled administration of funds. Lowitja Institute should administer the proportion of funding for research allocated to Aboriginal and Torres Strait Islander health research.



Background — The Murru Minya Study

This discussion paper has been prepared for Lowitja Institute by researchers on the Murru Minya study.

Murru Minya is a national study that aims to develop new knowledge about the implementation of ethical processes in Aboriginal and Torres Strait Islander health research. Murru Minya acknowledges that western epistemologies, or systems of knowledge, have positioned Aboriginal and Torres Strait Islander people as the subjects for investigation which has caused harm to people, land, and cultural practices. This research has resulted in little improvement in health and wellbeing outcomes and caused distrust among Aboriginal and Torres Strait Islander people towards research. Ethical guidelines and frameworks have been established internationally and nationally to ensure the safety of the participant is upheld in research practice. Since 1987, Aboriginal and Torres Strait Islander specific principles, values and guidelines have been developed, consulted, agreed, established and reviewed. However, nearly four decades on, there has been little national examination of the implementation of Aboriginal and Torres Strait Islander health research ethical principles, values and guidelines, and little critical analysis of how to improve research processes into the future.

The Murru Minya study aims to develop practical recommendations to strengthen research processes, the research workforce and ultimately improve health outcomes for Aboriginal and Torres Strait Islander people. The project takes four *baarra* (steps) to develop *gulbnha* (knowledge):

- Baarra One will collect knowledge, experiences, and wisdom from Aboriginal and Torres Strait Islander communities about their perceptions of health research.
- Baarra Two will explore barriers and enablers to conducting Aboriginal health research and adherence to ethical principles among researchers conducting Aboriginal and Torres Strait Islander health research.
- Baarra Three will explore the characteristics of HRECs operating in Australia, including their processes for overseeing and approving Aboriginal and Torres Strait Islander research.
- Baarra Four will develop a set of practical recommendations to support ethical conduct in Aboriginal health research into the future.

Murru Minya is led by Aboriginal and Torres Strait Islander academics and communities and governed by the National Health Leadership Forum.

The research protocol for this study can be found here: McGuffog R, Chamberlain C, Hughes J, et al *Murru Minya*–informing the development of practical recommendations to support ethical conduct in Aboriginal and Torres Strait Islander health research: a protocol for a national mixed-methods study, BMJ Open 2023;13:e067054. doi: 10.1136/bmjopen-2022-067054

Introduction

Health and medical research can have significant value to both individuals and society. High-quality health and medical research can help to identify new medical treatments and preventive measures that enable people to live longer and healthier lives, contribute to reduced healthcare costs and other economic benefits, and inform policy and practice decisions. However, the degree to which health and medical research is truly beneficial depends on many factors.

In Australia, Aboriginal and Torres Strait Islander people have been subject since the early days of colonisation to health and medical research that has been strongly influenced by colonial ideologies and caused significant harm including through forced experimentation, exploitation, and disruption to cultural practices. Non-Indigenous people did research on and about Aboriginal and Torres Strait Islander people; it was not *for* and *by* them.

This meant research was far from strengths-based, but was embedded in a deficit discourse, where Aboriginal and Torres Strait Islander people were regarded as the problem, rather than systemic practices that caused them harm, such as colonisation, genocide, and assimilation.

This historical and contemporary legacy of unethical research practice has resulted in a lack of trust in research and researchers by Aboriginal and Torres Strait Islander communities, amid a failure also to deliver improved health and wellbeing.

Since the 1980s at least, Aboriginal and Torres Strait Islander communities, organisations, advocates, and researchers have called for and led the development and implementation of ethical guidance and research governance processes to uphold Aboriginal and Torres Strait Islander ways of knowing, being and doing in health research, based on principles of self-determination, Aboriginal and Torres Strait Islander ownership, and control.

While formal guidelines that set out ethical practices for research involving Aboriginal and Torres Strait Islander people have been in place in Australia since the early 1990s, these have evolved over time and vary across the country in how they are operationalised. Still, at the time of writing this paper, fewer than half of Australian states and territories have established community-led ethical governance.

Lowitja Institute has a long history of supporting Indigenous-led research that reflects the priority needs of Aboriginal and Torres Strait Islander people and communities. Lowitja Institute generates its research agendas through a collective process of bringing together a range of Aboriginal and Torres Strait Islander stakeholders, who are grounded in community priorities.

Through this, Lowitja Institute has established the need for a National Aboriginal and Torres Strait Islander Health Research Ethics Committee, registered with the NHMRC, to ensure Aboriginal and Torres Strait Islander health research in Australia is conducted to the highest ethical and governance standards, and reflects the priorities, needs and values of Aboriginal and Torres Strait Islander peoples and communities.

In 2002, the NHMRC committed to investing a minimum of five per cent of its funding into Aboriginal and Torres Strait Islander health research (NHMRC 2002). More than 20 years on, there is a need to review current systems and processes of ethical practices to ensure the safety of Aboriginal and Torres Strait Islander people, communities and cultures in health and medical research. Acknowledging the legacy of Aboriginal and Torres Strait Islander leadership in prioritising and advancing Aboriginal and Torres Strait Islander human research ethical principles, values, and guidelines, it is imperative that future revision and direction also remains under Aboriginal and Torres Strait Islander leadership.

Objectives

This discussion paper has been developed in the context of ongoing conversations about the need to ensure that Aboriginal and Torres Strait Islander health research in Australia is conducted to the highest ethical and governance standards. This paper aims to provide an overview of current ethics approval and governance processes for Aboriginal and Torres Strait Islander health research in Australia, with the objective of identifying key gaps in ethical processes and practices, and areas of reform needed.

Key terms and context

It is critical to understand the history of ethics broadly before examining how we can improve ethical governance for Aboriginal and Torres Strait Islander health research. This section provides key terms and context for ethical research practice.

Ethics

Fundamentally, ethics is the philosophy of moral principles and judgements that guide human behaviour. Ethical behaviour is based on the values that people use to make decisions about what is good and bad, just and unjust, fair and unfair and right and wrong. Codes of ethics are sets of guidelines that are established to provide guidance about behaviour and a standard by which actions can be judged as right or wrong.

Research ethics

Research ethics are a set of moral principles, values, and standards that guide the conduct of research involving human subjects or animals. Codes of ethical research conduct outline the ethical standards that researchers must follow to protect the rights and welfare of research participants when conducting research, including the principles of informed consent, confidentiality, privacy, and non-maleficence (not causing harm). Codes of ethical research conduct are widely recognised and adopted by research institutions and organisations around the world.

Unethical human experiments

Guidelines and frameworks to guide ethical research practice largely emerged as a response to human rights abuses conducted under the guise of 'research' by Nazi doctors in Germany during World War Two (Shuster 1997). During this time, Nazi physicians conducted horrific experiments on humans, including children, at concentration camps. While details of these human rights abuses are difficult to read, they provide a sobering reminder of why we have ethical codes of practice in place today. This is by no means a complete list, but experiments included:

- **Freezing experiments.** These experiments were conducted with the intent of discovering ways to prevent and treat hypothermia. Up to 400 experiments were conducted with up to 300 victims. These included placing naked prisoners outside in temperatures below freezing for several hours and forcing prisoners to sit in tanks of freezing water for up to three hours. Re-warming was then attempted by different means, including placing victims into boiling water. Many prisoners died during the conduct of these experiments.
- **Sulfanamides to treat wound infections.** These experiments were conducted with the intent of discovering ways to treat battlefield wounds. Injuries were deliberately inflicted then infected with bacteria including streptococcus, gas gangrene, and tetanus. Infections were then purposefully aggravated by forcing wood shavings and ground glass into wounds. Infections were then treated with sulfanilamide and other drugs to determine their effectiveness.
- **Steralisation.** These experiments were conducted with the intent of developing an efficient way to sterilise millions of people. Men and women were subjected to various procedures that included genital mutilation, castration, the use of x-rays, surgery and various drugs.
- **Seawater experiments.** These experiments were conducted with the intent of determining methods of making seawater drinkable. Prisoners of war were deprived of all food and given only chemically processed seawater to drink. This resulted in significant harm.

The Nazi physicians involved in these experiments were trialled for war crimes at Nuremberg in 1945-46. The trial lasted 140 days and included 85 witnesses and almost 1,500 documents (Shuster 1997). Sixteen of the

doctors charged were found guilty and seven were executed. As a direct result of this trial and outcomes, *The Nuremberg Code* was developed to uphold human rights in research. The Nuremberg Code consists of 10 principles that focus on human rights for research participants. It has shaped ethical practice and guidelines globally.

Declaration of Helsinki

The *Declaration of Helsinki* (World Medical Association 2013) is a set of ethical principles that relate to medical research involving human subjects, inclusive of research on identifiable human material and data. The *Declaration of Helsinki* was developed by the World Medical Association in 1964 and has since been adopted globally, having a profound impact on how research is conducted. The Declaration outlines the responsibilities of investigators to research subjects, emphasises that it is the duty of the researcher or physician to ensure that all participants have the right to self-determination, integrity and privacy, and outlines the regulations for research institutions that receive health and medical research funding. These principles include that participants must give voluntary consent and that experiments must yield fruitful results, avoid unnecessary suffering and injury, have a degree of risk that does not exceed humanitarian importance, be conducted by qualified persons with proper preparation and facilities, and can be ended by the subject or scientist at any time to prevent injury, disability, or death.

National Health and Medical Research Council (NHMRC)

The NHMRC of Australia is a statutory body whose primary purpose is to fund and support research that improves the health and wellbeing of Australians. Under Section 10 of the National Health and Medical Research Council Act 1992 (Australian Federal Government 2006), the Chief Executive Officer of the NHMRC has a responsibility to issue human research guidelines that are developed by the Australian Health Ethics Committee, a Principal Committee of the NHMRC.

Statement on Ethical Conduct in Human Research

In 1966, the NHMRC developed the *Statement of Human Experimentation drawing on the Declaration of Helsinki* (World Medical Association 2013). Over time, the *Statement* has been revised to become NHMRC's *National Statement on Ethical Conduct in Human Research* (NHMRC, ARC & Universities Australia 2007) which guides all health and medical research in Australia. Since 1985, all health and medical research funded in Australia that involves humans or their data requires the enaction of the *National Statement on Ethical Conduct in Human Research* including the need for ethical approval by a registered HREC (Dunbar & Scrimgeour 2005). Responsibility for ethical design, review and conduct of human research in accordance with the National Statement primarily rests with individual researchers and their institutions, however researchers, HREC, funding organisations, agencies that set standards for research and governments all have an important role to play in ensuring that research is conducted in accordance with the National Statement (NHMRC, ARC & Universities Australia 2007).

Ethical approval

In Australia, it is a requirement that all human research is reviewed and approved by a HREC as a safeguard to ensuring that research is scientifically sound, adequately protects the rights and safety of participants, and adheres to organisational and legal requirements. Human research is any research that is conducted about people or with their data or tissue (NHMRC 2018). Ethics approval refers to the authorisation from a certified HREC to conduct a particular study.

Ethics approval processes aim to ensure that ethical standards are being upheld. To obtain ethics approval, a HREC will require an ethics application form to be completed and submitted together with a research protocol and associated documents such as participant information statements and consent forms. Ethics approval must be granted by an ethics committee that is properly constituted in accordance with the NHMRC National Statement (NHMRC, ARC & Universities Australia 2007) (see box 1). There are some exceptions to this requirement, however. Ethics approval is not needed if:

- research only uses publicly available information
- information is collected, or quality assurance or clinical audits are conducted, only for the purposes of improving processes within an organisation, where findings will not be published or presented outside of the organisation
- data is collected for teaching and learning purposes, where findings will not be publicly published or presented.

In Australia, the NHMRC National Statement outlines that the design, review and conduct of research must be guided by the values of research merit and integrity, justice, beneficence, and respect.

Research governance

Research governance refers to both a broad range of principles and standards that guide good research practice, and the specific frameworks through which institutions decide whether to authorise the conduct of a particular research project at a site and monitor its implementation (NHMRC 2011). Proper governance of research ensures that research meets its objectives while ensuring that it

BOX 1. NHMRC requirements for a properly constituted ethics committee (5.1.29-5.1.33 of the National Statement) NHMRC, ARC & Universities Australia 2007

A properly constituted ethics committee must have a minimum of eight members. As far as possible, there should be equal numbers of men and women and at least one third of the members should be from outside the institution for which the HREC is reviewing research. Members must include:

1. A chairperson, with suitable experience, whose other responsibilities will not impair the HREC's capacity to carry out its obligations under this National Statement.
2. At least two lay people, one man and one woman, who have no affiliation with the institution and do not currently engage in medical, scientific, legal or academic work.
3. At least one person with knowledge of, and current experience in, the professional care, counselling or treatment of people, for example, a nurse or allied health professional.
4. At least one person who performs a pastoral care role in a community, for example, an Aboriginal Elder, a minister of religion.
5. At least one lawyer, where possible one who is not engaged to advise the institution.
6. At least two people with current research experience that is relevant to research proposals to be considered at the meetings they attend. These two members may be selected, according to need, from an established pool of inducted members with relevant expertise.

No member may be appointed in more than one of the categories listed above. Wherever possible, one or more members should be experienced in reflecting on and analysing ethical decision-making. The institution should ensure that the HREC has access to the expertise necessary to enable it to address the ethical issues arising from the categories of research it is likely to consider.

conforms to relevant institutional, jurisdictional and national standards and applicable laws. Research governance aims to ensure that institution-specific considerations such as indemnity, intellectual property, resources, budget, and risk management are considered, and that the likelihood of adverse events occurring is minimised (NHMRC 2011). Each site where research is conducted sets their own processes and frameworks for assessing and providing research governance approvals. In Australia, the Australian code for the responsible conduct of research (NHMRC, ARC & Universities Australia 2018) promotes research governance by outlining the responsibilities of institutions and researchers in conducting research.

Aboriginal and Torres Strait Islander research governance

Aboriginal and Torres Strait Islander research governance refers to protocols, principles, processes, and ethical frameworks that guide research involving Indigenous peoples and communities. It ensures that research upholds the rights and responsibilities of Aboriginal and Torres Strait Islander people and communities to be involved in all aspects of research that concerns them, and that research is safe and respects the values, diversity, priorities, needs and aspirations of Aboriginal and Torres Strait Islander peoples and communities. Appropriate research governance promotes Aboriginal and Torres Strait Islander community ownership, consent, control, and engagement and ensures that key principles including respect, reciprocity, responsibility, equality, survival and protection, and spirit and integrity are met by research practices.

For more information about Aboriginal and Torres Strait Islander research governance:

- Bond, C., Foley, W. & Askew, D. 2016, '"It puts a human face on the researched" – A qualitative evaluation of an Indigenous health research governance model', *Australian and New Zealand Journal of Public Health,* vol, 40, p. S89-S95. https://doi.org/10.1111/1753-6405.12422
- Duke D.L.M., Prictor, M., Ekinci, E., Hachem, M. & Burchill L.J. 2021, 'Culturally Adaptive Governance—Building a New Framework for Equity in Aboriginal and Torres Strait Islander Health Research: Theoretical Basis, Ethics, Attributes and Evaluation', *International Journal of Environmental Research and Public Health,* vol. 18, no. 15, p. 7943. https://doi.org/10.3390/ijerph18157943
- Burchill, L. J., Kotevski, A., Duke, DLM., Ward, JE., Prictor, M., Lamb, KE. & Kennedy, M, 2023, 'Ethics guidelines use and Indigenous governance and participation in Aboriginal and Torres Strait Islander health research: a national survey', *Med J Aust,* vol. 218, no. 2, p. 89-93. doi: 10.5694/mja2.51757

Current principles and governance for ethical research in Aboriginal and Torres Strait Islander health

Aboriginal and Torres Strait Islander people's experiences of health research

The history of Aboriginal and Torres Strait Islander people and health research cannot be considered independently of the history of colonisation and the devastating impact this has had and continues to have on the lives of Aboriginal and Torres Strait Islander people. Colonisation brought with it medical researchers who examined, measured, monitored, and documented Aboriginal and Torres Strait Islander people without consent, and with the goal to continue the justification of stealing their lands. Ancestral remains of Aboriginal and Torres Strait Islander people and sacred objects were sent to museums, universities, and private collections around the world for display and analysis by anatomists and anthropologists. Photographs of Aboriginal body parts were printed in medical journals beside photos of both chimpanzee and gorilla body parts, with comments about similarities (Cunningham 1889).

During the 20th century, research conducted on Aboriginal and Torres Strait Islander people continued to be exploitative, stigmatising, insensitive and invasive, and was often conducted for the benefit of non-Indigenous researchers' careers rather than for Aboriginal and Torres Strait Islander people and communities (NAHS Working Party 1989; Johnstone 1991). Research was conducted using Western research approaches that marginalised and ignored Aboriginal and Torres Strait Islander epistemologies, and without control, ownership, or conceptual involvement of Aboriginal and Torres Strait Islander people (Bainbridge 2015). This included degrading experiments conducted with children who were part of the Stolen Generations, including testing the effects of different diets and medications on children without informed consent and measuring skulls and facial features in an attempt to prove racial superiority. These practices seeded significant mistrust of research and researchers by Aboriginal and Torres Strait Islander people. Similar experiences of research have been reported among Indigenous peoples globally, resulting in the word 'research' having been deemed 'one of the dirtiest words in the Indigenous world's vocabulary' (Smith 1999: 1). As a consequence, requests to participate in research are often met with fear and distrust by Aboriginal and Torres Strait Islander people (Holmes et al. 2002), regardless of how well-intentioned a project or group of researchers are.

> The health survey, the census taker, the keeper of public hospital morbidity records, all evoke memories of the anthropologist, the missionary and those police who were actively involved in the institutionalisation of Aboriginal children and the coercive regulation of reserve and mission life. In such a history the anthropologist of the 1930s blends easily with the health researcher of the 1990s, although the circumstances and intent may differ greatly. (Anderson 1996: 154)

For more information about Aboriginal and Torres Strait Islander people's experiences with health research:

- Bainbridge, R., Tsey, K., McCalman, J., Kinchin, I., Saunders, V., Lui, F. W., Cadet-James, Y., Miller, A. & Lawson, K. 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, p. 696. https://doi.org/10.1186/s12889-015-2052-3-
- Rigney, L, 2001, 'A First Perspective of Indigenous Australian Participation in Science: Framing Indigenous Research Towards Indigenous Australian Intellectual Sovereignty', *Kaurna Higher Education Journal,* vol. 7, p. 1-13.
- Dudgeon, P., Kelly, K., & Walker, R. 2010 'Closing the gaps in and through Indigenous health research: Guidelines, processes and practices', *Australian Aboriginal Studies,* vol. 2, p. 81-91.

The development of Aboriginal and Torres Strait Islander ethics principles and processes

In the early 1970s, Aboriginal and Torres Strait Islander people began calling for the prioritisation, negotiation, development and endorsement of specific principles, guidelines and governance of health research involving Aboriginal and Torres Strait Islander people and their data. In 1983, John Liddle and Barbara Shaw, writing on behalf of the Central Australian Aboriginal Congress, published *'Some Research Guidelines'* that insisted on Aboriginal control of, and participation in, research, the adoption of non-invasive and culturally sensitive methodologies, the pursuit of research of need and benefit to communities, and full Aboriginal control over the dissemination of findings (see CAAG 2022a).

In 1986, a conference in Alice Springs that was jointly convened by the NHMRC and Menzies Foundation aimed to explore the health needs of Aboriginal and Torres Strait Islander people and identify priorities for the provision of healthcare. Issues raised at the conference by Aboriginal delegates culminated in the history, politics and processes of research, and notably unethical research, becoming a central focus of sessions and of the resulting conference outcomes. Recommendations that emerged from the conference related specifically to ethical aspects of research in Aboriginal health and principles for the funding and organisation of research (Houston 1987), including that:

- 'Ethical guidelines for health research involving Aborigines be established.'
- 'That these ethical guidelines be established by a forum of Aboriginal people, representative of Aboriginal Communities and community controlled organisations throughout Australia within six months.'
- 'That the close relationship between ethical guidelines and criteria for funding research projects be recognised and that the health research involving Aborigines be very heavily weighted towards problems as perceived by Aboriginal communities.'
- 'That there should be Aboriginal involvement in Aboriginal research (i) setting priorities; (ii) methods; (iii) ethical issues; and (iv) implementation' (Houston 1987).

1936	NHMRC was established (known then as the Australian Medical Research Council)
1966	NHMRC's Statement on Human Experimentation was published
1983	**Publication of 'Some Research Guidelines' by the Central Australian Aboriginal Congress**
1985	**The Aboriginal Health & Medical Research Council of New South Wales (AH&MRC), then known as the Aboriginal Health Resource Co-Op, was established**
1986	**'Research Priorities in Aboriginal Health' conference held in Alice Springs/Mparntwe, and South Australian Aboriginal Health Research Ethics Committee established**
1987	**Workshop on Ethics of Aboriginal Health research convened in Camden, NSW** Australian Research Council published discussion paper on human research ethics
1989	**First National Aboriginal Health Strategy published**
1991	**NHMRC releases Interim 'Guidelines on ethical matters in Aboriginal and Torres Strait Islander Research'** **Darwin based Aboriginal Ethics Sub-Committee established**
1996	**Western Australian Aboriginal Health Information and Ethics Committee established** **AH&MRC HREC established**
2000	**AIATSIS first published ethics guidelines, 'The AIATSIS Guidelines for Ethical Research in Australian Indigenous Studies (GERAIS)'**
2003	**NHMRC publishes: 'Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research'**
2005	**NHMRC publishes: 'Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics'**
2006	Australian Health Ministers Advisory Council (AHMAC) agreed to the establishment of a nationally harmonised approach to scientific and ethical review of multi-centre health and medical research (did not cover Aboriginal and Torres Strait Islander research)
2011	**AIATSIS updated 'Guidelines for Ethical Research in Australian Indigenous Studies' which focused on Indigenous authority, ownership of traditional knowledge, and the establishment of reciprocal partnerships**
2013	National Mutual Acceptance Scheme commences operations
2018	**NHMRC publishes: 'Keeping research on track II and Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders'**
2020	National Mutual Acceptance scheme updated to include data linkage studies
2022	Northern Territory amalgamated the two HRECs into one HREC, and also into one Research Governance Office for NT Health service providers

Note: Milestones in bold are specific milestones related to Aboriginal and Torres Strait Islander ethics processes. Broader non-Aboriginal ethics milestone are unbolded.

The courage of delegates to directly challenge the way research was conducted at this conference became pivotal in the history of the development of Aboriginal and Torres Strait Islander ethics principles and guidelines. In 1987, a workshop on Ethics of Aboriginal Health Research was convened in Camden NSW by the NHMRC with the express aim of developing a set of ethical guidelines and working out the mechanisms by which these could be enacted. The workshop resulted in the development of a set of principles, standards and rules to guide ethical research involving Aboriginal and Torres Strait Islander people, which emphasised the need for researchers to obtain informed consent from Aboriginal and Torres Strait Islander participants, to respect Aboriginal and Torres Strait Islander knowledge and culture, and to work in partnership with Aboriginal and Torres Strait Islander communities (Houston 1987). In 1991, the NHMRC released interim '*Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*' (NHMRC 1991) following a six-year consultation process (NHMRC 2002; Kim 2003). These documents have set out what the standards for good research practice are, and repositioned Aboriginal and Torres Strait Islander peoples from subjects of research to partners in research.

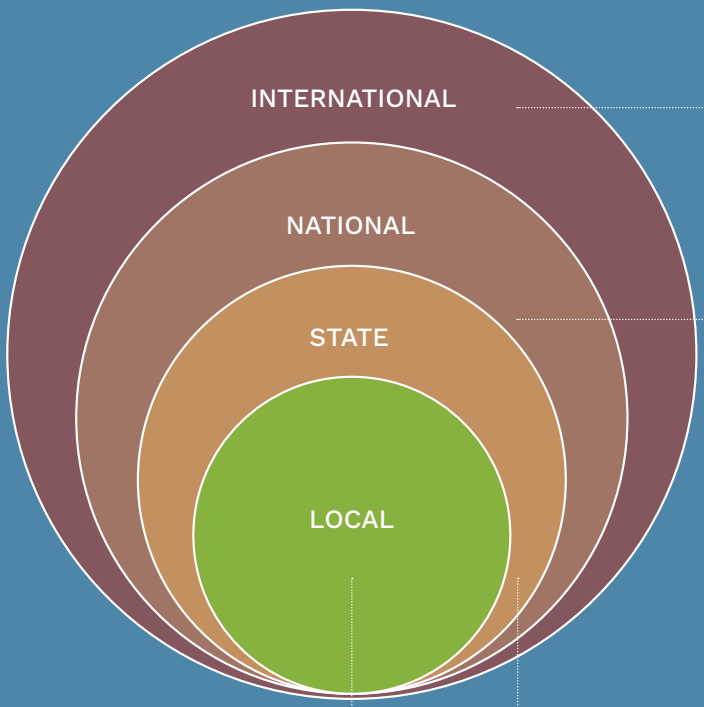
For more information about the history of development of principles and processes:

- Houston, S. 1987, Report of the National Workshop on Ethics of Research in Aboriginal Health, National Aboriginal and Torres Strait Islander Health Organisation, Sydney.
- Humphrey, K. 2003, 'Setting the Rules: The development of the NHMRC guidelines on ethical matters in Aboriginal and Torres Strait Islander health', *New Zealand Bioethics Journal,* vol. 4, no. 1, p. 14-19.
- Humphrey, K. 2002, *The Development of the National Health and Medical Research Council Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research: A Brief Documentary and Oral History. Discussion Paper No.7,* VicHealth Koori Health Research & Community Development Unit, Melbourne.

Overview of Aboriginal and Torres Strait Islander ethical principles and guidelines

With growing recognition by Aboriginal and Torres Strait Islander and mainstream health research authorities of the need to improve the responsiveness of research and accountability of researchers, and to uphold the rights of Aboriginal and Torres Strait Islander people in research practice, various codes, principles, frameworks and guidelines have been developed. All principles and 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 people (NHMRC 2003). Acknowledging the diversity of Aboriginal or Torres Strait Islander communities, cultures and customs across the nation, various documents outlining processes, principles and guidelines for conducting Aboriginal and Torres Strait Islander health research have been published, adopted, and revised across the country (NHMRC 2003; NHMRC 2018; AH&MRC 2020; AIATSIS 2020; Morey 2021) that draw on place-based priorities and practices. It is critical that researchers read, understand, and apply these principles to their research practice.

Figure 1. Summary of principles and guidelines that apply to research being conducted with Aboriginal and Torres Strait Islander people in Australia.



INTERNATIONAL

- World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects (World Medical Association 2013).

NATIONAL

General guidelines

- National Statement on Ethical Conduct in Human Research 2007 (updated 2018) (National Health and Medical Research Council, Australian Research Council et al. 2007).
- Australian code for the responsible conduct of research, 2018(National Health and Medical Research Council 2018).
- Privacy Act 1988 (Cth).

Aboriginal-specific guidelines

- Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (National Health and Medical Research Council 2018).
- Australian Institute of Aboriginal and Torres Strait Islander Studies Code of Ethics for Aboriginal and Torres Strait Islander Research(Australian Institute of Aboriginal and Torres Strait Islander Studies 2020).
- Keeping Research on Track II (2018)(National Health and Medical Research Council 2018).

STATE

- NSW: AH&MRC Ethical Guidelines: Key Principles (2020)(Aboriginal Health and Medical Research Council 2020)
- SA: South Australian Aboriginal Health Research Accord: Companion Document, Version 2, 2021 (Morey 'K' On behalf of the Wardliparingga Aboriginal Health Equity Research Theme 2021).

LOCAL

- Differs by location.

National ethical principles and guidelines for Aboriginal and Torres Strait Islander health research

Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (NHMRC 2018a)

Early development

As the leading body for health and medical research, the NHMRC is responsible for setting ethical standards for research involving humans. In 1991, the NHMRC published the first ever guidance to researchers and research ethics committees on the ethical conduct of research involving Aboriginal and Torres Strait Islander peoples in Australia, titled '*Interim Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*' (NHMRC 1991). The guidelines were specifically developed in response to concerns raised by Aboriginal and Torres Strait Islander communities about the lack of cultural sensitivity and respect in research conducted in their communities. The guidelines provided specific recommendations about community consultation and involvement, informed consent and the use of cultural knowledge and heritage. These guidelines provided a foundation for the development of the more comprehensive guidelines that exist today.

The Australian Health Ethics Committee is a committee of the NHMRC that is responsible for providing advice and guidance on ethical issues in health and medical research in Australia. From 1994-1999 it worked to revise the *NHMRC Statement on Human Experiementation and Supplementary Notes* (1992), which resulted in the *National Statement on Ethical Conduct in Research Involving Humans* (NHMRC 1999) (otherwise known as 'the National Statement') which included protections for all Australians, including Aboriginal and Torres Strait Islander peoples.

As part of this process, the Australian Health Ethics Committee received consistent feedback from submissions and public forums about the need for a separate and complementary set of guidelines specifically focused on research in Aboriginal and Torres Strait Islander health that updated the 1991 interim guidelines. This led to a review of the *National Statement and Interim Guidelines* (NHMRC 1991) over the Australian Health Ethics Committee's three year term. Aboriginal researcher and community research partnership coordinator Daniel McAullay and Australian Health Ethics Committee member Robert Griew engaged in conversations with a range of stakeholders in Aboriginal and Torres Strait Islander health research. They found that while researchers were aware of the Interim Guidelines, they were not necessarily aware of the application of the National Statement to Aboriginal and Torres Strait Islander peoples. After an annotated bibliography of the international literature on the ethics of Aboriginal and Torres Strait Islander health research was published, a workshop attended by representatives from the National Aboriginal Community Controlled Health Organisation and its state/territory affiliates, researchers, HRECs, government and other Aboriginal participants considered all aspects of the material brought together by the processes to date. In 2003, the AHEC published *Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research* (NHMRC 2003), which aimed to provide a comprehensive framework for the ethical conduct of research involving Indigenous peoples in Australia and outlined six principles to guide the conduct of research.

Recent revisions

In 2013, Lowitja Institute and AIATSIS worked together on behalf of the NHMRC to evaluate the two key NHMRC documents: *'Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research 2003'* and its companion document *'Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005'*. The evaluation involved extensive consumer engagement through consultation and a series of workshops held in each state and territory. This process resulted in the production of an evaluation report (AIATSIS & the Lowitja Institute 2013) and literature review (Lowitja Institute & AIATSIS 2013) to inform revision of the guidelines. In 2015, the Indigenous Research Ethics Guidelines Review Working Committee

was established by the NHMRC to revise the 2003 Guidelines and *Keeping Research on Track,* using the outcomes of both the literature review and evaluation report. The impetus for review was to address the changing landscape of research involving Aboriginal and Torres Strait Islander communities in Australia. The Indigenous Research Ethics Guidelines Review Working Committee was made up of various stakeholders including the Chair of AIATSIS Research Ethics Committee and Ethics Advisor, AHEC committee members, researchers with expertise in Aboriginal and Torres Strait Islander research, health policy, education and research experts, and the Social Justice Commissioner. After public consultation on the revised feedback in 2017, the Committee formed the final guidelines, which were recommended for release by Australian Health Ethics Committee and the Council of NHMRC. *'Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: guidelines for researchers and stakeholders'* (NHMRC 2018a) was published in 2018 to replace the *'Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research 2003'*.

Both the 2003 and 2018 guidelines have six core values that are intended to ensure all research undertaken with Aboriginal and Torres Strait Islander people and community respects the shared values of Aboriginal and Torres Strait Islander peoples, is relevant and meets the needs and priorities of Aboriginal and Torres Strait Islander peoples, develops long-term relationships, and forms best-practice ethical standards of research. Each core value in the guideline is linked to the National Statement. It is expected that the guidelines are used alongside the *National Statement on Ethical Conduct in Human Research, Australian Code for Responsible Conduct of Research,* and *Keeping research on track II* (NHMRC, ARC & Australian Universities 2007; NHMRC, ARC & Universities Australia 2018; NHMRC 2018b). Researchers must demonstrate how the guidelines are applied to each stage of the research process: conceptualisation, development and approval, data collection and management, analysis, report writing, and dissemination. The guidelines state that non-Aboriginal HRECs should consider referring research proposals to an Aboriginal HREC for approval, create an Aboriginal and Torres Strait Islander sub-committee or reference group, or expand committee membership to include Aboriginal and Torres Strait Islander members and community.

AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research (AIATSIS 2020)

AIATSIS published its first ethics guidelines in 1999. These aimed to provide guidance for researchers working with Aboriginal and Torres Strait Islander communities, including practical advice on issues such as informed consent, respecting Aboriginal and Torres Strait Islander knowledge and intellectual property, and engaging with communities in culturally appropriate and respectful ways. The GERAIS guidelines were first updated in 2012 to reflect the developing standards of ethical research with Aboriginal and Torres Strait Islander people (AIATSIS 2012). In 2020, AIATSIS undertook its most recent revision of the guidelines in collaboration with the NHMRC, Australian Research Council, and the National Indigenous Australians Agency. The *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research* (AIATSIS 2020) was published in October 2020. Each revision reflects critical areas of work and scholarship to further improve research practice and ethical conduct.

The AIATSIS (2020) Code provides guidelines for ethical research practice that respects the rights and interests of Aboriginal and Torres Strait Islander communities. The code is based on four key principles that are identified as necessary to conducting ethical and responsible research with Aboriginal and Torres Strait Islander people and communities. These are:

1. Indigenous self-determination
2. Indigenous leadership
3. Impact and value
4. Sustainability and accountability.

The AIATSIS (2020) Code is intended to be implemented alongside the National Statement to guide researchers, institutions, funding bodies and HRECs to conduct ethical research that respects the rights and interests of Aboriginal and Torres Strait Islander communities. The code defines Aboriginal and Torres Strait Islander research 'as research that concerns or impacts Aboriginal and Torres Strait Islander peoples in any of the following ways:

- the research is about Aboriginal and Torres

Strait Islander peoples, societies, culture and/or knowledge, Aboriginal and Torres Strait Islander policies or experience

- the target population is Aboriginal and Torres Strait Islander individuals, groups, communities or societies
- the target population is not explicitly Aboriginal and Torres Strait Islander individuals or communities but the research population includes a significant number of Aboriginal and Torres Strait Islander people
- Aboriginal and/or Torres Strait Islander people have been incidentally recruited and researchers wish to do separate analysis of Indigenous-specific data
- there are Aboriginal and Torres Strait Islander individuals or communities contributing to the research
- there is new or pre-existing data related to Aboriginal and Torres Strait Islander peoples being used in the research.'

State-based ethical principles and guidelines for Aboriginal and Torres Strait Islander health research

Acknowledging the diversity of Aboriginal and Torres Strait Islander people, states and territories have also established appropriate processes and guidelines relevant to their peoples. These guidelines are used in conjunction with international and national statements and guidelines.

AH&MRC Ethical Guidelines: Key Principles (2020) V2.0 (AH&MRC 2020)

In response to the overwhelming amount of research published on Aboriginal and Torres Strait Islander people and communities without consultation and with negative framing, the AH&MRC Health Research Ethics Committee was established in 1996. Shortly after, it published the *'Guidelines for research into Aboriginal health 1999'* (since updated to 2016) (AH&MRC 2016), drawing from a variety of conferences, statements, reports and guidelines in Aboriginal and Torres Strait Islander health research. These guidelines alongside the Key Principles have guided the HREC's considerations for ethical approvals in conjunction with the National Statement.

> Our Committee's review is a necessary step to assist researchers to design meaningful, ethical, and culturally appropriate research projects to minimise harm and mitigate risks for Aboriginal Communities participating in research. (AH&MRC 2020: 4)

This work was further updated in 2020, in the publication, *'AH&MRC Ethical Guidelines: Key Principles'* (AH&MRC 2020) (replacing *Guidelines for research into Aboriginal Health 2016*) for researchers and reviewing committees to ensure that Aboriginal and Torres Strait Islander health research is done in a culturally appropriate way, and upholds Aboriginal and Torres Strait Islander people and community leadership in the research process.

Approval from the AH&MRC HREC is required when research involves Aboriginal and Torres Strait Islander people in New South Wales and any of the following apply (AH&MRC 2020: 8):

- the experience of Aboriginal people is an explicit focus of all or part of the research
- data collection is explicitly directed at Aboriginal peoples
- Aboriginal peoples, as a group, are to be examined in the results
- the information has an impact on one or more Aboriginal communities
- Aboriginal health funds are a source of funding.

AH&MRC detail five key principles for submitting an application for review by the AH&MRC Ethics Committee. It states that, 'All key principles must be embedded throughout the application in the form of established processes and mechanisms, this will ensure that Aboriginal needs and perspectives have been meaningfully considered' (AH&MRC 2020: 5-8).

The five key principles are as follows:

1. **Net benefits for Aboriginal people and communities:** The benefits of the research may be for Aboriginal health in general or specifically for the health of Aboriginal people and communities participating in the project.
2. **Aboriginal community control of research:** Aboriginal community control must be a key focus of all projects affecting Aboriginal people. This means that at all stages of the research project, Aboriginal people and communities participating in or affected by the research will be fully informed about and agree with the purposes and conduct of the project.
3. **Cultural sensitivity:** Cultural protocols and community decision making processes will vary between Aboriginal communities: researchers should consider this when designing a project.
4. **Reimbursement of costs:** There must not be any imposition upon Aboriginal people and communities to be involved in the research project.
5. **Enhancing Aboriginal skills and knowledge:** The project should build the capacity of Aboriginal people to participate in and lead research projects. Individuals may be from an Aboriginal community organisation, Aboriginal reference group, participants or researchers on the project team.

The AH&MRC updated principles require that Aboriginal governance is embedded in research. This includes direct Aboriginal community controlled health service involvement, the formation of an Aboriginal reference group to provide guidance to research, and the involvement of Aboriginal researchers.

South Australian Aboriginal Health Research Accord: Companion Document 2014, Version 2 (revised 2021) (Morey 2021)

The South Australian Health and Medical Research Institute (SAHMRI) was established in 2009 as South Australia's first independent health and medical research institute. It includes the Wardliparingga Aboriginal Health Equity unit, which aims to create equity through research that improves the health and wellbeing of Aboriginal and Torres Strait Islander people.

In response to Aboriginal and Torres Strait Islander community calls for reform in the way Aboriginal health research is conducted, the *South Australian Aboriginal Health Research Accord* (SAAHRA) was developed by Wardliparingga through consultation with Aboriginal peak bodies in South Australia, community Elders, the Council of Aboriginal Elders of South Australia, Aboriginal Health Council of South Australia, and the university sector. The principles detailed in the accord were formed using existing literature, and consultation through Wardliparingga Aboriginal health workshops. These workshops were held in 2013, and hosted over 80 participants from a variety of backgrounds including full and part-time researchers, Aboriginal and non-Aboriginal people and service providers conducting research in their workplace, clinicians, Aboriginal community members, policy and program staff in government, health service planners and decision makers (Morey 2021: 2-3).

> The Accord represents Wardliparingga's response to one of these identified priorities: **ensuring that research is done the right way**. (Morey 2021: 3)

In 2014, the Accord was officially signed by the University of Adelaide, University of South Australia, Flinders University, Council of Aboriginal Elders South Australia, Aboriginal Health Council of South Australia, and SAHMRI. It details nine key principles when conducting Aboriginal and Torres Strait Islander health research in South Australia (Morey 2021: 9):

1. **Priorities:** Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability.
2. **Involvement:** The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research.
3. **Partnership:** Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures.
4. **Respect:** Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge.

5. **Communication:** Communication must be culturally and community relevant and involve a willingness to listen and learn.
6. **Reciprocity:** Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.
7. **Ownership:** Researchers should acknowledge, respect, and protect Aboriginal intellectual property rights and ensure transparent negotiation of intellectual property use and benefit sharing.
8. **Control:** Researchers must ensure the respectful and culturally appropriate management of all biological and non-biological research materials.
9. **Knowledge translation and exchange:** Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice.

Congress Research Core Values (CAAG 2022b)

The Central Australian Aboriginal Congress (known as Congress) is the largest Aboriginal community controlled health organisation in the Northern Territory, providing a comprehensive, holistic and culturally-appropriate primary health care service to Aboriginal people living in and nearby Alice Springs/Mparntwe, including six remote communities; Amoonguna, Ntaria (and Wallace Rockhole), Ltyentye Apurte (Santa Teresa), Utju (Areyonga) and Mutitjulu.

To establish preferred ways of conducting Aboriginal health research in central Australia, the Congress led *Aremella Arratyenye-ileme: Doing It Right* research team deliberated with the Amoonguna, Mpwelarre, Mutitjulu, Western Aranda and Utju remote health boards, and the town-based Congress research sub-committee from 2018 to 2020. From this consultation, the Congress Research Core Values were derived from adaptation of the NHMRC's six core values. The adapted core values reflect conversations of past research, community priorities, and community involvement. The Congress Research Core Values are commitment, uphold culture, justice and fairness, sharing, respect and relationships, and responsibility. The values as adapted from the NHMRC (CAAG 2022b):

- spirit and integrity became **commitment**
- cultural continuity became **uphold culture**
- equity became **justice and fairness**
- reciprocity became **sharing**
- respect became **respect and relationships**
- responsibility remained as **responsibility**.

These adapted values align with Congress's vision and mission statements by emphasising key principles that are crucial in conducting research with integrity, cultural sensitivity, fairness, and a commitment to building and maintaining relationships with the communities involved.

Researchers must align with the *Congress Strategic Plan and Research Strategy 2019-2023* for their research to be considered for approval.

Local ethical principles and governance for Aboriginal and Torres Strait Islander health research

Localised research principles and governance refer to ethical and cultural considerations that are specific to a particular Aboriginal and Torres Strait Islander community or geographical area. These principles and governance frameworks reflect the unique cultural values, beliefs, and practices of the community and aim to ensure that research conducted within the community is respectful, relevant, and beneficial. Below are some examples of localised research principles and governance frameworks from across Australia.

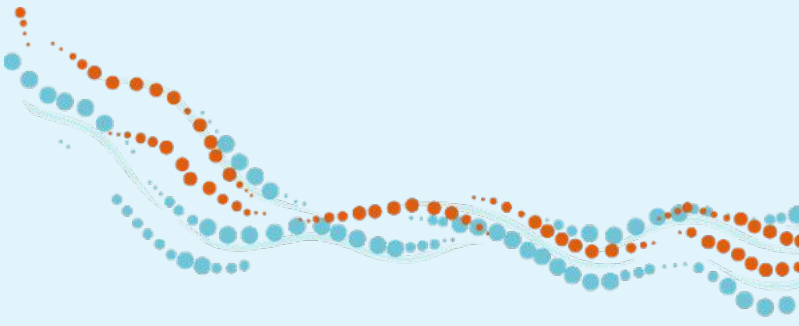
Principles of KAHRA (KAHRA 2022)

The Kimberley Aboriginal Health Research Alliance (KAHRA) was established in 2019 following acknowledgement of the significant research burden in the Kimberley region. The aim of KAHRA was to bring together health services, Aboriginal communities and research organisations operating in the Kimberley region to plan, design and oversee the conduct of research to ensure that all research conducted in the region is purposeful, beneficial and community and health service driven.

This is reflected in the 'Principles of KAHRA July 2022' (KAHRA 2022) alongside KAHRA's objectives, which assert 'the importance of community control, the recognition of Indigenous knowledge and culture, and the need for research to be relevant and beneficial to the community.'

The objectives of KAHRA include:

1. **Aboriginal leadership:** Ensuring Aboriginal people are the leaders of Aboriginal health research in the Kimberley and Aboriginal culture is the foundation of all research practice.
2. **Community ownership and participation:** Facilitating community ownership of research and the active participation of community members across all stages of the research process.
3. **Improvement to health services:** Facilitating and commissioning research aimed at improving the efficacy of health services and health care such as improved access, quality, staff retention and evaluation research.
4. **Capacity building:** Enhancing Aboriginal health research capability in the Kimberley across Aboriginal community members, non-Aboriginal researchers and health services staff, including by increasing the number of Kimberley Aboriginal community members working in research.
5. **Coordination and collaboration:** Increasing the coordination of Aboriginal health research across the Kimberley and promoting collaboration between Kimberley Aboriginal communities, researchers and health services.
6. **Creating change (translation):** Ensuring the results of research are used to change what is done, whether through changes to policy or practices.
7. **Cultural integrity and research rigour:** Ensuring research in the Kimberley is of the highest quality and rigour, acknowledging that methods which incorporate Aboriginal cultural ways of knowing and doing deliver the most sustainable results.



Waminda: South Coast Women's Health and Wellbeing Aboriginal Corporation

In response to the community's need for a service dedicated to Aboriginal women and to account for the difficulties accessing mainstream health services, the Aboriginal Women's Health Centre on the South Coast was established in 1984. The service was funded under Jilimi the Shoalhaven Women's Health and Resource Corporation which discontinued in the late 1980s. As such, the South Coast Women's Health and Welfare Aboriginal Corporation, Waminda was officially established in 1990.

Waminda is an Aboriginal health service and local leader in research. Researchers wanting to partner with Waminda in research must apply for approval through an online form to the research committee consisting of staff and community members. Only research that aligns with Waminda's strategic goals and objectives as detailed in *Waminda's Research Strategy & Priorities 2020-2025* is considered. These goals ensure that research activities are in line with and support the self-determination of Aboriginal women and their families and are of benefit to the service and community. Waminda and the Aboriginal community are positioned as active participants of the research and committed to employing and training Aboriginal researchers, with all research conducted with the service to be accountable, culturally safe, and relevant.

> 'We are committed to ensuring any research we commission and/or partner with others to do, will contribute towards improving the quality of life of Aboriginal peoples and to a greater understanding and respect for First Nations culture and ways of being, knowing and doing'. (Waminda 2023a)

Inala Indigenous Health Service: Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care

The Inala Indigenous Health service (otherwise known as the Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care) was established in 1995. The service aims to improve the health of Aboriginal and Torres Strait Islander people through culturally appropriate health care, as reflected in its research focus on improving access to health services and culturally appropriate service delivery, chronic disease, and community health priorities and needs.

As well as an internal Research Committee, Inala has a Community Jury comprised of 12-14 Aboriginal and/or Torres Strait Islander peoples, which was established in 2010 to engage local community in the service's research agenda. By approving and governing research conducted with Inala, the Community Jury's role is to ensure research is ethical, appropriate and locally supported.

Any research that involves Inala is first assessed by the internal Research Committee who assess the benefits to community as well as the capacity of the service to engage in the research. Once approved, proposed projects are then presented to the Community Jury, who assess the methodology, cultural appropriateness, and the proposed projects alignment to local community priorities. Once the proposed project is endorsed by the two bodies, it is then able to progress to revision by a Health Research Ethics Committee (HREC). The Inala Community Jury provides ongoing oversight over the approved project.

All research conducted by and with the Inala Indigenous Health service must comply with the AIATSIS Code of Ethics (AIATSIS 2020) as well as the NHMRC's ethical guidelines for research with Aboriginal and Torres Strait Islander Peoples (NHMRC 2018).

Aboriginal and Torres Strait Islander specific HRECs and sub-committees in Australia

Processes for obtaining ethical approval of Aboriginal and Torres Strait Islander health research

Any research involving Aboriginal and Torres Strait Islander communities must adhere to state and federal legislation, as well as ethical guidelines and codes of practice. As outlined in this report, these include:

- The NHMRC *Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander research* (2018).
- The NHMRC *National Statement on Ethical Conduct in Human Research*. This guideline outlines key ethical principles that must be followed by researchers and institutions, including respect for human dignity, autonomy, and privacy, and a commitment to minimising harm and maximising benefits.
- The Australian Code for the Responsible Conduct of Research. This national set of guidelines for the ethical and responsible conduct of research in Australia provides principles and guidelines for researchers and institutions to ensure that research is conducted in a way that is ethical, transparent, and accountable.
- The Privacy Act 1988 (Cth). This law regulates the collection, use, and disclosure of personal information by Commonwealth government agencies and private sector organisations. Researchers must ensure that they comply with the privacy principles set out in the Act when collecting and handling personal information as part of their research.
- Any other state or territory legislation or guidelines where their research is being conducted.

One mechanism to uphold governance of ethical research practice is through HRECs who receive, review, approve and monitor research. In Australia, HRECs must be registered with the National Health and Medical Research Council (NHMRC), which outlines requirements for both establishing and operating committees. As of December 2022, there were 189 registered HRECs that sit within universities, government and non-government departments and some private organisations. Registered committees must abide by specific rules about membership, roles and responsibilities of members, processes used in assessments, and annual reporting requirements.

Of the 189 registered HRECs, there are three Aboriginal HRECs that have specialist expertise in reviewing research involving Aboriginal and Torres Strait Islander people. These committees include:

- The Aboriginal Health & Medical Research Council Ethics Committee (NSW)
- The Aboriginal Health Research Ethics Committee (SA)
- The Western Australian Aboriginal Health Ethics Committee (WAAHEC).

Aboriginal HRECs are distinguished by majority membership of Aboriginal and Torres Strait Islander people who have knowledge and expertise in cultural protocols, community values, and ethical considerations related to research involving Aboriginal and Torres Strait Islander peoples. The three Aboriginal HRECs are based in Aboriginal Community Controlled Organisations, which upholds the original recommendations made by Aboriginal and Torres Strait Islander people in 1987. Aboriginal HRECs ensure that there is appropriate governance of research practice and direct accountability to Aboriginal and Torres Strait Islander people regarding health research.

There are no Aboriginal specific ethics committees currently operating in the Australian Capital Territory, Victoria, Tasmania, and Queensland. A properly constituted Aboriginal ethics committee was established at the Victorian Aboriginal Health Service (VAHS) in the mid-1990s, however it operated only for a short time (Stewart & Pyett 2005).

Northern Territory Aboriginal Sub-Committee

The Northern Territory has a partnership HREC between Northern Territory Health and the Menzies School of Health Research. This is not an Aboriginal HREC but does include an Aboriginal sub-committee which, the Menzies School website notes, 'advises the main committee on issues relating to research specifically involving Aboriginal and Torres Strait

Islander people'. Research involving Aboriginal and Torres Strait Islander people is reviewed by the Aboriginal sub-committee prior to review by the HREC.

Kimberley Aboriginal Health Planning Forum Sub-committee

The Kimberley Aboriginal Health Planning Forum (KAHPF), is the peak regional health forum for improving health outcomes for Aboriginal people in the Kimberley. To support and progress its work, the KAHPF has established sub-committees, including the Research Sub-committee which was established in 2006 to guide research activity in the region.

The Forum does not grant ethics approval, but provides advice to potential researchers in the region, and provides advice and recommendations to the WAAHEC. Research projects conducted in the Kimberley region must undertake assessment by the Sub-committee before being submitted to or reviewed by the WAAHEC.

The Sub-committee updated its requirements for research in 2023. All proposed research projects for the Kimberley region must meet the following conditions in order to receive regional support:

- There is consultation with each individual organisation that is involved in the project (noting that Kimberley Aboriginal Medical Services does not provide region-wide support). An outcome of this would be a detailed letter/s of support from the relevant organisation/s.
- If organisations do not have capacity to be involved in a proposed project, they will say no. If an organisation approached for involvement in research does not respond, this should be taken as declining involvement.
- Aboriginal health research projects in the Kimberley require the meaningful and informed involvement of Kimberley Aboriginal people. It is expected that local Aboriginal people will be included as Investigators on projects.

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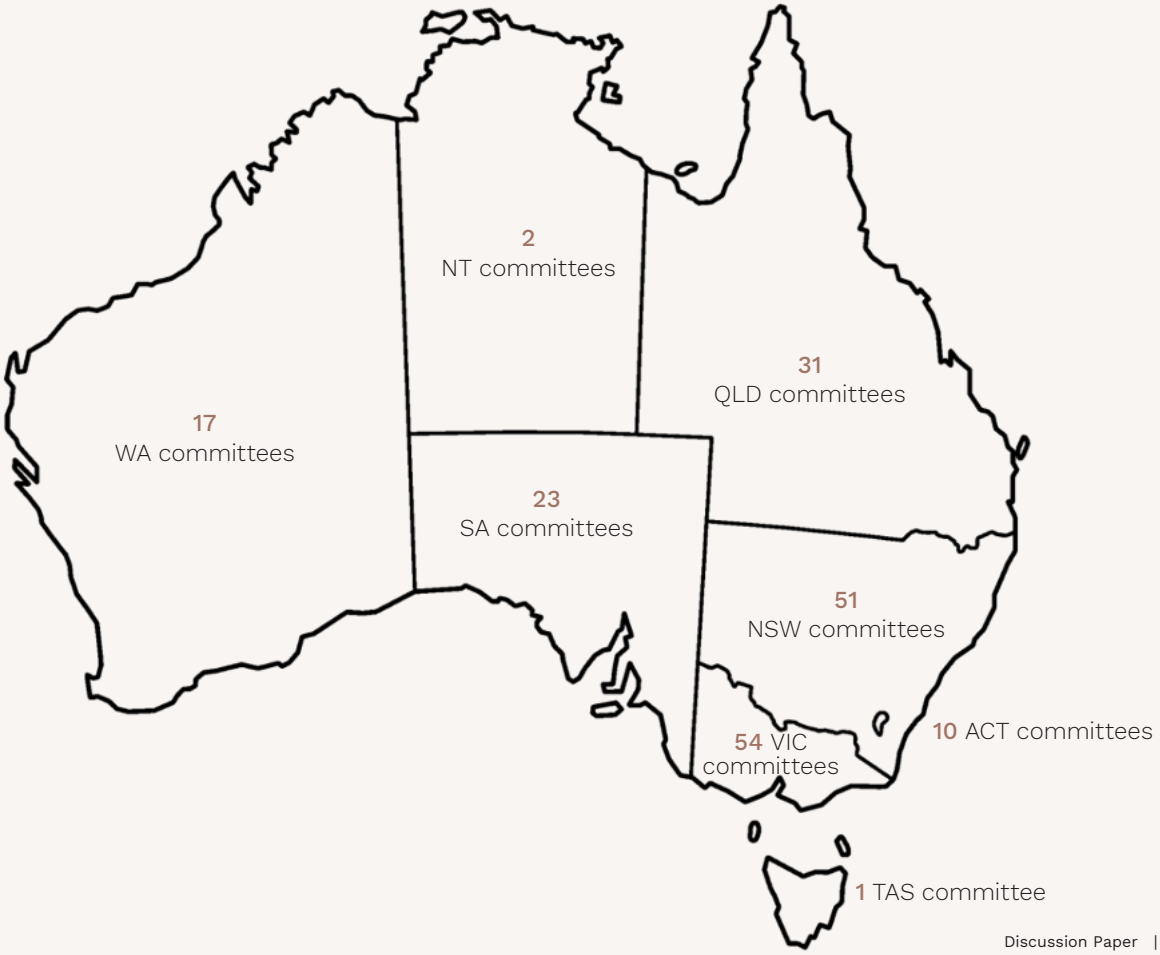


- Any costs incurred by organisations in support of the research (e.g., clinic space, transport, human resources, participation in research) are budgeted for and reimbursed to the organisation if required.
- Researchers commit to providing updates, research findings and practical implications to the involved organisations, communities, and individuals throughout the project. This could form part of the organisation's letter of support, or a written research agreement.
- Researchers commit to working with the involved organisations at the end of the project to help make use of the findings, including advocacy for funding or resources where relevant.

As part of assessing projects for cultural security, benefit and burden, the following requirements will also be considered:

- Methods that are appropriate for the Kimberley setting.
- Lack of duplication of current or previous research.
- Availability of sufficient resources.
- Useful outcomes for Kimberley Aboriginal people.
- Consistency with the Principles of KAHRA that have been endorsed by representatives of Aboriginal Community Controlled Health Services and WA Country Health Service (WACHS).

Challenges

While the guidance is clear that any research involving Aboriginal and Torres Strait Islander peoples, or their data, requires ethical review, this must be completed by a HREC with relevant skills and experience. This ethical review involves multiple stakeholders, including researchers, institutions, expert committees established to assist in these processes, and the reviewing HRECs in each state. It is the responsibility of these groups to ensure that they have adequate expertise and provide appropriate oversight of Aboriginal and Torres Strait Islander research. Ultimately, institutions are responsible for establishing their own procedures for the ethical review of human research, including that involving Aboriginal and Torres Strait Islander people. While some institutions mandate that ethics review must be completed by a registered Aboriginal HREC, with the institution ratifying the approval once granted by the Aboriginal HREC, there is no national requirement that this occurs. Some institutions require review by a registered Aboriginal HREC on an ad hoc basis, and some do not require this at all.

Figure 2 outlines the different processes for seeking ethical approval across the country.

Aboriginal and Torres Strait Islander health research ethical principles and guidelines are clear about what is expected of researchers and institutions when conducting health research with Aboriginal and Torres Strait Islander people. While these principles have undergone revision and implementation, ethical governance of research through HRECs has not had the same level of attention.

This raises the question: How can Aboriginal and Torres Strait Islander people be assured ethical principles and guidelines are upheld if there is no Aboriginal and Torres Strait Islander governance through a HREC?

Figure 2. Criteria for obtaining approval by jurisdiction

In WESTERN AUSTRALIA, research must receive ethics approval from WAAHREC if:

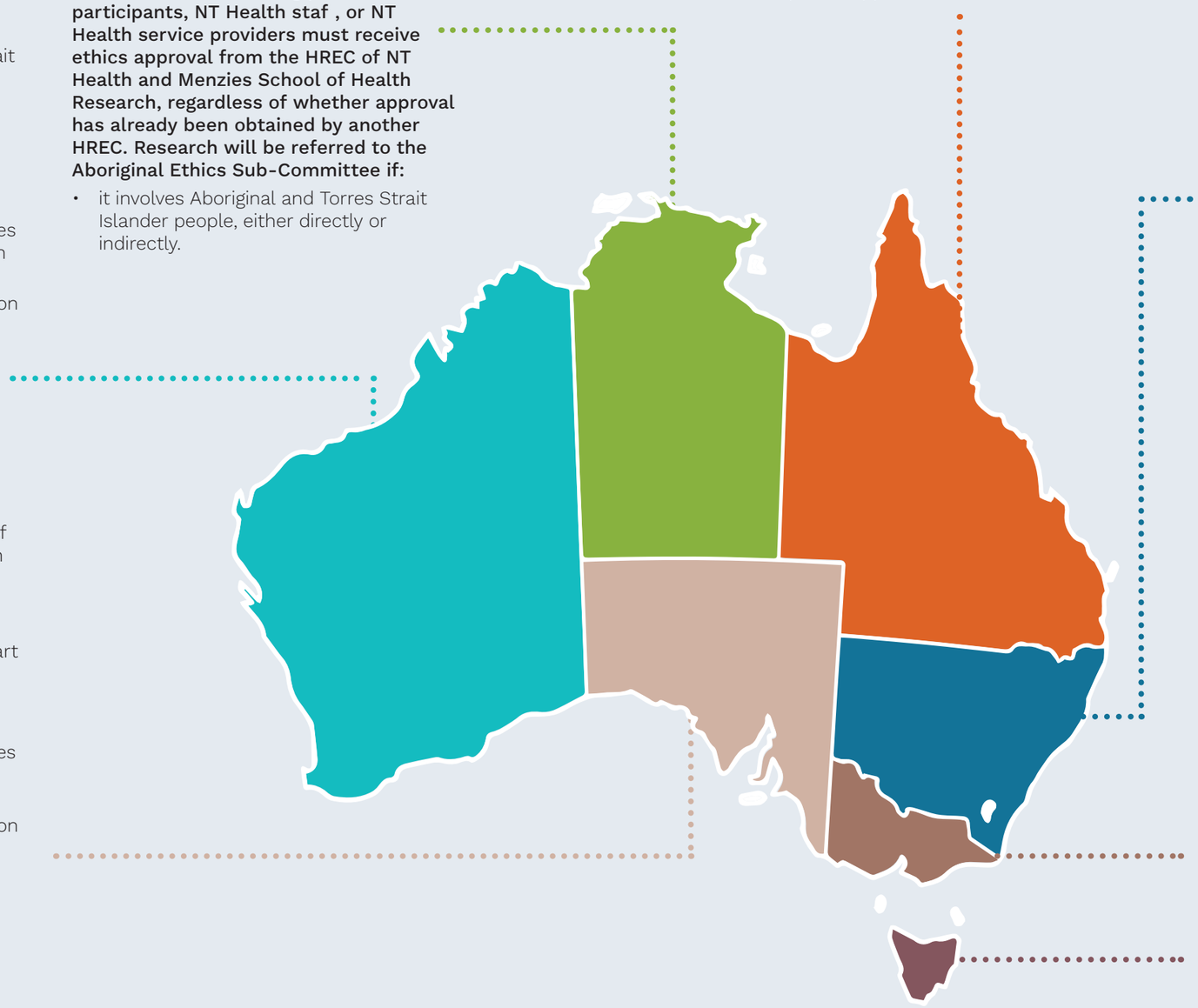
- the research is related to health and wellbeing; and
- the experience of Aboriginal and Torres Strait Islander people is an explicit focus of all or part of the research; or
- data collection is explicitly directed at Aboriginal people; or
- research outcomes explicitly related to Aboriginal people; or
- it is proposed to conduct sub-group analyses and separately analyses Aboriginal people in the results; or
- the information, potential over-representation in the dataset, or geographic location has an impact on one or more Aboriginal communities; or
- government Aboriginal health funds are a source of funding.

In SOUTH AUSTRALIA, research must be approved by the South Australian AHREC if:

- the primary research goals and questions of study are directly related to health research and wellbeing; and
- the experience of Aboriginal and/or Torres Strait Islander people (hereafter referred to as Aboriginal) is an explicit focus of all or part of the research; or
- data collection is explicitly directed at Aboriginal people; or
- it is proposed to conduct sub-group analyses and separately analyse Aboriginal people in the results; or
- the information, potential over-representation in the dataset or geographic location has an impact on one or more Aboriginal communities; or
- governmental Aboriginal health funds are a source of funding.

In the NORTHERN TERRITORY, all research that actively accesses NT Health sites including patient participants, NT Health staf , or NT Health service providers must receive ethics approval from the HREC of NT Health and Menzies School of Health Research, regardless of whether approval has already been obtained by another HREC. Research will be referred to the Aboriginal Ethics Sub-Committee if:

- it involves Aboriginal and Torres Strait Islander people, either directly or indirectly.



In **QUEENSLAND**, there is no specific requirement to obtain Aboriginal-specific approval.

In NEW SOUTH WALES, research must receive ethics approval from the AH&MRC if:

Essential criteria:

- the experience of Aboriginal people is an explicit focus of all or part of the research
- data collection is explicitly directed at Aboriginal peoples
- Aboriginal peoples, as a group, are to be examined in the results
- the information has an impact on one or more Aboriginal communities
- Aboriginal health funds are a source of funding.

Desirable and additional criteria:

- any of the five factors listed above are present; or
- the Aboriginal experience of the medical condition being studied is known, or is likely, to be different from the overall population; or
- there are Aboriginal people who use the services being studied in distinctive ways, or who have distinctive barriers that limit their access to the services; or
- Aboriginal people are known, or likely, to be significantly over-represented in the group being studied (compared to the 3.4% of total NSW population) and/or it is proposed to separately identify data relating to Aboriginal people at any stage in the project.

In **VICTORIA**, there is no specific requirement to obtain Aboriginal-specific approval.

In **TASMANIA**, there is no specific requirement to obtain Aboriginal-specific approval.

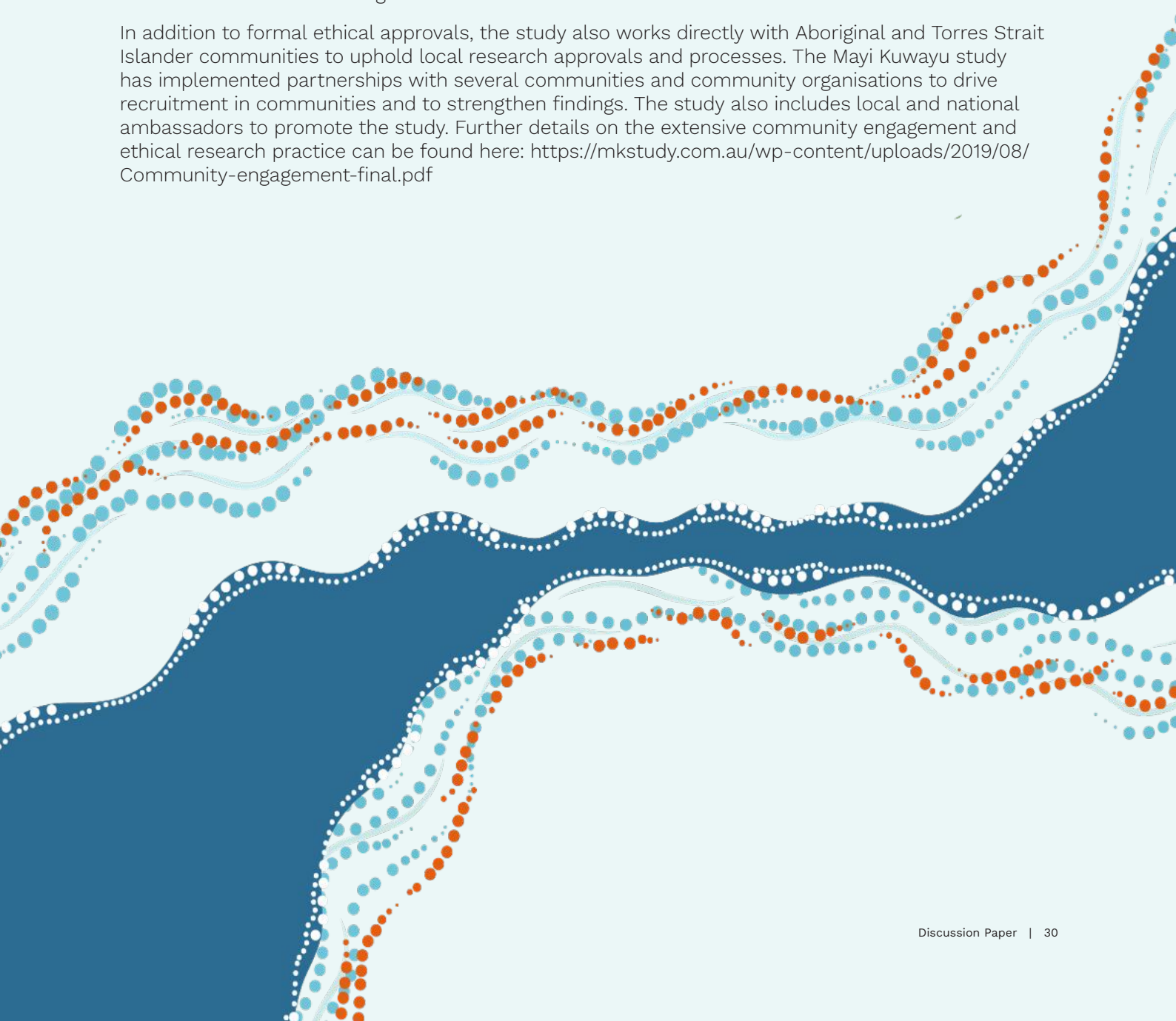
CASE STUDY FOR OBTAINING ETHICAL APPROVAL: MAYI KUWAYU

Mayi Kuwayu is a national longitudinal cohort study of Aboriginal and Torres Strait Islander wellbeing. The study aims to provide evidence on drivers of health and wellbeing with a focus on culture.

The study received approval from a total of 12 national and state/territory committees, including:

- the Australian Institute of Aboriginal and Torres Strait Islander Studies
- Australian National University HREC
- Aboriginal Health and Medical Research Council
- Aboriginal Health Research Ethics Committee SA
- ACT Health
- Central Australian Human Research Ethics Committee (CAHREC)
- Metro South Queensland
- NT Department of Health & Menzies School of Health Research
- Nunkuwarrin Yunti (SA)
- St Vincent's Hospital Melbourne HREC
- University of Tasmania (UTAS)
- Western Australian Aboriginal Health Ethics Committee.

In addition to formal ethical approvals, the study also works directly with Aboriginal and Torres Strait Islander communities to uphold local research approvals and processes. The Mayi Kuwayu study has implemented partnerships with several communities and community organisations to drive recruitment in communities and to strengthen findings. The study also includes local and national ambassadors to promote the study. Further details on the extensive community engagement and ethical research practice can be found here: https://mkstudy.com.au/wp-content/uploads/2019/08/Community-engagement-final.pdf



From principles to practice: are Aboriginal and Torres Strait Islander ethical principles being upheld?

Despite the existence of long-standing guidelines and a national commitment to uphold and promote ethical research involving Aboriginal and Torres Strait Islander people, there remains continued concern that current approval processes do not fully uphold key values and principles. In this context, it is important to identify and address gaps in current practices in order to ensure that ethical standards are upheld and the rights and wellbeing of Aboriginal and Torres Strait Islander communities are protected.

Representation of Aboriginal and Torres Strait Islander people on HRECs

According to section 5.1.30 of the National Statement on Ethical Conduct in Human Research (NHMRC, ARC & Universities Australia 2007), a properly constituted HREC must include eight members including: a chairperson with suitable experience, at least two lay people, at least one person with knowledge of and current experience in the professional care, counselling or treatment of people (e.g. a nurse or allied health professional), at least one person who performs a pastoral care role in a community (e.g. an Aboriginal Elder, a minister of religion), a lawyer, and at least two people with current research experience that is relevant to research proposals to be considered at the meetings they attend. While these criteria around membership are clear, they are variably enacted.

The NHMRC reports annually on the activity of HRECs and Certified Institutions based on annual reports submitted by committees. These reports include data about HREC composition, as well as the number of committees that have Aboriginal and Torres Strait Islander committee members. In the period between 2016 and 2021 between 6% and 9% of HRECs reported that they did not meet the minimum membership requirements during the reporting period. Critically, in the same time period, only between 26% and 32% of HRECs reported they had an Aboriginal and/or Torres Strait Islander person included as a member of the committee.

How can we be assured that the spirit and integrity of NHMRC Ethical Guidelines are upheld without Aboriginal and Torres Strait Islander people being represented on every HREC?

If we're not on the committees, is there Aboriginal and Torres Strait Islander oversight of Aboriginal and Torres Strait Islander health research?

The National Statement specifies that for research involving Aboriginal and Torres Strait Islander people 'HREC process must have included assessment by or advice from: people who have networks with Aboriginal and Torres Strait Islander Peoples and/or knowledge of research with Aboriginal and Torres Strait Islander Peoples; and people familiar with the culture and practices of the Aboriginal and Torres Strait Islander people with whom participation in the research will be discussed'. The 2021 NHMRC report on the activity of HRECs includes reporting on the mechanisms used by HRECs for review of health research proposals involving Aboriginal and Torres Strait Islander peoples. This report found that most research (73%) underwent standard HREC review. **This does not mean that Aboriginal or Torres Strait Islander people were represented on these committees or were involved in the ethical review of the research.** Only 37% of all research involving Aboriginal and Torres Strait Islander

people was referred to a HREC that specialises in assessing Aboriginal and Torres Strait Islander health research.

How can we be assured that the spirit and integrity of NHMRC Ethical Guidelines are upheld when most research undergoes standard HREC review with limited or no Aboriginal and Torres Strait Islander involvement?

Currently, the establishment of Aboriginal-specific ethics committees is not a requirement under the National Statement. However, jurisdictional differences in requirements for approval has created a fragmented system. There are significant variances in Aboriginal and Torres Strait Islander ethical governance over research, and varying implementation of ethics principles. There have been repeated calls for Aboriginal HRECs to be established. In 2012-13 the Lowitja Institute (AIATSIS & the Lowitja Institute 2013: 9) recommended that 'Human Research Ethics Committees with a specific focus on Aboriginal and Torres Strait Islander health be set up and resourced in those jurisdictions where they do not yet exist'. There is a clear need for consistency in Aboriginal and Torres Strait Islander-specific HREC review across the country.

Duplication of ethics approval processes for multi-jurisdictional and national research

Currently, responsibilities for appropriate oversight of cross-jurisdictional Aboriginal and Torres Strait Islander research rests with multiple stakeholders including researchers, institutions, reviewing HRECs in each state, and any expert committees that may be established to assist any of these parties in the fulfilment of their responsibilities. The need to obtain ethics approval in each state adds significantly to the cost and time taken to complete research, with questionable additional protection to participants. Large-scale changes to ethics review processes in Australia over the past 15 years have reduced the time taken to obtain ethics approval for some cross-jurisdictional research. The National Mutual Acceptance Scheme is a national system that supports the acceptance of a single scientific and ethical review for multi-centre research conducted in publicly funded health services across jurisdictions in Australia. This means that researchers are only required to submit an ethics application to one HREC which is then accepted by HRECs in other states without the need to apply for additional approvals in each state. The National Mutual Acceptance scheme has been in operation for review of multi-centre clinical trials since 2013 and was expanded to include all human research commencing from December 2015. In 2020, it was updated to include multi-jurisdictional data linkage studies. All states and territories are currently part of the National Mutual Acceptance Scheme. However, the National Mutual Acceptance Scheme specifically excludes the consideration of Aboriginal and Torres Strait Islander research.

How can we be assured that the spirit and integrity of NHMRC Ethical Guidelines are upheld in a National Mutual Acceptance Scheme if there are no mandates for Aboriginal and Torres Strait Islander oversight in standard the HREC review?

Cross-jurisdictional and national projects that include Aboriginal and Torres Strait Islander people continue to present challenges including extensive time to submit multiple applications, the need to duplicate and modify content across different ethics application forms, and variability in application requirements and submission systems (see case study: National Indigenous Eye Health Survey). These challenges mean that the approval processes for this type of research are often time-consuming, resource-intensive and duplicative. Complexity of research governance procedures and ethical approval processes for multi-jurisdictional research carries the risk that research becomes so expensive and time consuming that it become infeasible. Time spent writing, rewriting and submitting multiple ethics applications to meet different ethics requirements is counter-intuitive to better engagement with communities on the ground. The longer ethics approvals take, the less time and resources are available at the end of the research for feedback

to the participants and communities involved and to maximise the impact of research (Greville et al. 2019). There is limited evidence to suggest that the current duplication of ethical reviews is best practice to uphold Aboriginal and Torres Strait Islander rights in safe and ethical research practice.

There have been consistent calls for the establishment of a National Aboriginal Ethics Committee to approval cross-jurisdictional and national research. In 1987, the National Workshop on Ethics of Research in Aboriginal Health called for a national Aboriginal and Torres Strait Islander community controlled HREC to both approve national studies and to inform the distribution of Aboriginal and Torres Strait Islander health research expenditure (Houston 1987). In 2012-13 Lowitja Institute was commissioned by the NHMRC to conduct a review and make recommendations to improve the effectiveness of ethics guidelines for Aboriginal and Torres Strait Islander health research (AIATSIS & Lowitja Institute 2013). This review recommended that 'Human Research Ethics Committees with a specific focus on Aboriginal and Torres Strait Islander health be set up and resourced in those jurisdictions where they do not yet exist, with a **national committee or process to consider multi-site, multi-jurisdictional research proposals**.'

To date, a national committee has not been established, nor has the expenditure of Aboriginal and Torres Strait Islander health research funding been offered to an Aboriginal Community Controlled Organisation. Lowitja Institute is a commissioning body for Aboriginal and Torres Strait Islander community-driven health research, however funding offered to Lowitja Institute is not proportionate to national commitments to health research and should be increased. While the Australian Institute of Aboriginal and Torres Strait Islander Studies Research Ethics Committee is registered with the NHMRC and is recognised as a national HREC that provides nationally-endorsed ethical approval for research related to Aboriginal and Torres Strait Islander peoples and collections, it is not endorsed by Aboriginal and Torres Strait Islander community controlled health services as providing national ethics approval as is it not specific to health research.

T TH T
RESEARCH: NATIONAL INDIGENOUS EYE HEALTH STUDY

The National Indigenous Eye Health Survey was a national multistage randomised cluster study that aimed to assess the prevalence and principle causes of vision impairment, the utilisation of eye care services, the barriers to eye health, and the impact of vision impairment among Aboriginal and Torres Strait Islander peoples (Taylor & Fox 2008; Studdert et al. 2010). It aimed to recruit a representative sample of 3,000 adults and children from 30 sites across all Australian states and territories. Approval for the study involved:

- Correspondence with 73 entities over a 22-month period. This included obtaining approval from 8 HRECs and 31 different community organisations whose sign-off on the project was a pre-condition of HREC approval. Researchers also voluntarily consulted with an additional 24 organisations whose consent was not a precondition to ethics approval, but whom an ethics committee or community organisation suggested consulting.
- Every jurisdiction except Queensland and Victoria required approval by a state-level HREC (or, in the case of Victoria, an HREC with state-level approval authority), and the Northern Territory required two separate state-level approvals.
- 7/8 HRECs accepted the standardised National Ethics Application form.
- HRECs identified a total of 60 ethical issues in review, and community consultations identified 20 issues.
- Investigators estimated that over a 22-month period ethics approval processes consumed 50% of a full-time staff member's time, and 15% of time for each of the three chief investigators.

For further reading on the practical challenges of undertaking ethical Aboriginal and Torres Strait Islander research:

- Gower, G. C. 2012, 'Ethical research in Indigenous Australian contexts and its practical implementation. Proceedings of Innovative research in a changing and challenging world', Australian Multicultural Interaction Institute, Phuket, p. 47-58. https://ro.ecu.edu.au/cgi/viewcontent.cgi?article=1130&context=ecuworks2012

Responsibility for ensuring that human research is ethically designed and implemented in accordance with the National Statement lies with individual researchers and their respective institutions. A 2022 Australian Universities review of research policy infrastructure designed to engage with Aboriginal and Torres Strait Islander research and researchers concluded that "there is a need for policy harmonisation at the institutional level, a reform to ethics processes and research reporting, and best practice guides for researchers and external research participants to assist with implementation and compliance" (Bowrey, Watson & Hadley 2022: 8).

The original guidance on ethical research practice was clear. However, it remains unclear how researchers are upholding these principles, values and guidelines in the research processes.

Where to from here?

Aboriginal and Torres Strait Islander people have the right to lead research and the reforms required to uphold our rights in research, and to safeguard from further harms caused by research. More than 37 years on from the first Aboriginal and Torres Strait Islander-led guidance on ethical research practice and governance, a large proportion of the original recommendations are yet to be enacted. This discussion paper has been developed with an acknowledgement of the leadership and wisdom of Aboriginal and Torres Strait Islander people who have generated national discussions on this topic for decades. We acknowledge that Aboriginal and Torres Strait Islander people are the original researchers of this place and have already invested their intellectual thought leadership and direction on what constitutes ethical research conduct. This paper aims to gather this knowledge and leadership, draw on current practice, and provide broad recommendations to funding bodies, government, research institutions, academics journals and individuals to uphold Aboriginal and Torres Strait Islander rights to safe and ethical research practice.

Recommendations

1. A National Aboriginal and Torres Strait Islander Ethics Committee was called for in 1987. This should be established to oversee the conduct of national and multi-jurisdictional health research.
2. That state-based HRECs be established in all states and territories. There are still four states and territories where state-based committees do not exist. State-based AHRECs should be properly constituted, registered with NHMRC, and located in the Aboriginal and Torres Strait Islander community controlled health sector.
3. Increased infrastructure to support Aboriginal and Torres Strait Islander community controlled HRECs in all states and territories acknowledging the increase in research and need to support the critical functions of all state-based AHRECs.
4. All institutions that conduct Aboriginal and Torres Strait Islander health research should facilitate agreement making with state-based Aboriginal and Torres Strait Islander HRECs, ensuring there are systems in place to monitor that research practices reflect Aboriginal and Torres Strait Islander ethical research principles.
5. Nationally consistent guidelines be developed, endorsed and upheld by the NHMRC, institutions and hospitals, clarifying the type of research that requires ethics approval from an AHREC.
6. Nationally endorsed and accredited training in Aboriginal and Torres Strait Islander health research be developed and implemented to build the capacity of the Aboriginal and Torres Strait Islander health research sector including HRECs.
7. That the NHMRC National Statement be updated to reflect that a properly constituted HRECs require at least one committee member to be Aboriginal and/or Torres Strait Islander.
8. In 1987 Aboriginal and Torres Strait Islander people called for ethical publishing practice. Ethical publishing guidelines be developed through consultation and consensus with Aboriginal and Torres Strait Islander people and AHRECs. These guidelines must be upheld by researchers and national and international peer-reviewed journals.
9. That NHMRC review and evaluate research commissioning processes. In 1987, Aboriginal and Torres Strait Islander people identified that the most effective way of maintaining appropriate control over the ethical behaviour of researchers and their initiatives was for Aboriginal and Torres Strait Islander community controlled administration of funds. Lowitja Institute should administer the proportion of funding for research allocated to Aboriginal and Torres Strait Islander health research.

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