

Upholding our rights in research: calling for urgent investment in Aboriginal and Torres Strait Islander health research ethics

Growth in Aboriginal and Torres Strait Islander health research requires urgent investment in Aboriginal and Torres Strait Islander ethical governance

Indigenous peoples have been conducting research to understand complex systems of knowledge since time immemorial.¹ The embodiment of principles aligned with Indigenous ways of knowing, being and doing is central to the legacy of this expert research practice. In this perspective article, we draw on our lived experiences and a review on the field of practice of ethical research.

Before we offer this commentary, it is critical we position ourselves as the authors. I, Janine Mohamed, am a *Narrunga Kaurna* woman from South Australia living on the lands of the *Wurundjeri* peoples. I am a wife, a mother of five. I have dedicated 25 years to working in Aboriginal and Torres Strait Islander health. Many of these years have been working for the Aboriginal Community Controlled Health Sector and as the Chief Executive Officer (CEO) of the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINA). I am currently the CEO of the Lowitja Institute — Australia's national institute for Aboriginal and Torres Strait Islander health research. I, Michelle Kennedy, am a *Wiradjuri* woman raised on unceded *Worimi* lands. I am a social worker, mother of four, Research Fellow at the University of Newcastle, and Executive Manager of Research and Knowledge Translation at Lowitja Institute. I held the Aboriginal representative seat on the University's Human Research Ethics Committee (HREC) for over two years, and lead the national study *Murru Minya*, which explored the conduct of ethical research in Aboriginal and Torres Strait Islander health.² Our critical reflections expressed in this article are informed by our social and cultural world view. We will offer insight into the gaps in ethical research infrastructure despite the increasing investment in Aboriginal and Torres Strait Islander health research and evaluation. We ask the question: what is needed to uphold ethical governance of Aboriginal and Torres Strait Islander health research?

Since the 1980s, all individuals and institutions conducting health and medical research have been required by the National Health and Medical Research Council (NHMRC) of Australia, and most funding bodies, to acquire approval from a registered HREC before accessing funding sources and research commencement.³ This is in line with the *National Statement on Ethical Conduct in Human Research*, which draws on evidence and findings of inhumane research conducted in Nazi Germany.^{4,5} However, since colonisation, Aboriginal and Torres Strait Islander peoples have been subject to ongoing unethical and inhumane research.⁶⁻⁸ In an attempt

for protection, Aboriginal and Torres Strait Islander people have acted swiftly and led the prioritisation, consultation, development and consensus of specific ethical guidance and principles for Aboriginal and Torres Strait Islander health research since 1987.³ Ethical guidance clearly states that appropriate ethical governance that includes, but is not limited to, ethical review and approval is critical to the application of Aboriginal and Torres Strait Islander health research. However, more than three decades on, Aboriginal and Torres Strait Islander ethical guidelines have been reviewed⁹ and revised, but little investment has been made to uphold the ethical principles and practices established for and by Aboriginal and Torres Strait Islander people. Despite decades of Aboriginal and Torres Strait Islander leadership in ethics, there remains significant limitations to current governance, oversight and approval of research being conducted on Aboriginal and Torres Strait Islander peoples. Notably, there has never been appropriate national and state-based resourcing of Aboriginal and Torres Strait Islander community controlled HRECs.

There are currently about 200 HRECs registered with the NHMRC. Of these, only three are Aboriginal and Torres Strait Islander and located in community controlled organisations (Box). There are currently no registered Aboriginal and Torres Strait Islander community controlled HRECs in Victoria, Tasmania or Queensland,¹⁰ and there is no Torres Strait Islander controlled HREC.

Despite Aboriginal and Torres Strait Islander health research being conducted nationwide and predominately by non-Indigenous peoples and institutions, there is limited investment and resourcing, by those profiting from the academic field, to uphold the ethical guidance and principles developed by Aboriginal and Torres Strait Islander people.

The large proportion of HRECs registered with the NHMRC are located within universities and hospitals. Both institutions financially benefit from the approval of ethics applications, as the health and education investment correlates to academic outputs and training. Institution-based HRECs have up to one designated position on the ethics committee for "at least one person who performs a pastoral care role in a community, for example, an Aboriginal Elder [or] a minister of religion".⁴ This means involvement of an Aboriginal and Torres Strait Islander reviewer for ethics applications is at the institution's discretion. In comparison, the Aboriginal Health and Medical

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Aboriginal and Torres Strait Islander Human Research Ethics Committees registered with the National Health and Medical Research Council

State	Ethics committee
New South Wales	Aboriginal Health and Medical Research Council (AHMRC) of NSW
Western Australia	WA Aboriginal Health Committee
South Australia	Aboriginal Health Research Ethics Committee
Northern Territory	Aboriginal Sub-Committee to the NT Department of Health and Menzies School of Health Research
Australian Capital Territory, Victoria, Tasmania, Queensland	No Aboriginal and Torres Strait Islander health-specific ethics committee

Research Council (AHMRC) in New South Wales has 13 Aboriginal and Torres Strait Islander members on the Aboriginal and Torres Strait Islander community controlled HREC, which includes four Elders and a male and female Aboriginal co-chair. Most of the AHMRC HREC members work voluntarily, and the organisation does not benefit from health and education investment the same way an institution would. Aboriginal Community Controlled Organisations, including those contributing to the field of research, are not awarded investments aligned with universities, such as the National Competitive Research Grants Program and the Research Block Grant funding.¹¹

Research should be of benefit to Aboriginal and Torres Strait Islander peoples. Over the past two years, extensive work has occurred through partnerships between governments and the Aboriginal and Torres Strait Islander Community Controlled Health sector to revisit and refresh critical national health policy documents.¹²⁻¹⁴ These policy and partnership reforms will drive a greater investment in research and evaluation, adding to the 5% investment committed by the NHMRC and the Medical Research Future Fund's ten-year investment plan (2022–23 to 2031–32) of \$87.5 million toward the Indigenous Health Research Fund.¹⁵ Acknowledging this upcoming growth in Aboriginal and Torres Strait Islander health research, we must address the critical question of how these funded research projects will uphold the rights of Aboriginal and Torres Strait Islander people to ethical and respectful research practice and ensure appropriate ethical governance.

All research involving Aboriginal and Torres Strait Islander peoples should be deemed safe and respectful by Aboriginal and Torres Strait Islander peoples. As such, all research involving Aboriginal and Torres Strait Islander peoples should include Aboriginal and Torres Strait Islander Community Controlled health ethical approvals. However, there is no national infrastructure to support this.

Ensuring appropriate mechanisms for Aboriginal and Torres Strait Islander ethical governance is everybody's responsibility. We therefore emphasise the need for institutions, including hospitals and universities, to establish systems to ensure Aboriginal and Torres Strait Islander health ethics is upheld, while

acknowledging the right to Aboriginal and Torres Strait Islander ethical research governance. This can be facilitated through making agreements with state-based Aboriginal and Torres Strait Islander HRECs and ensuring there are systems in place to monitor that researchers in all institutions are upholding Aboriginal and Torres Strait Islander ethical research practices.

The current Aboriginal and Torres Strait Islander Community Controlled ethical research governance infrastructure is inadequate and under-resourced. The anticipated acceleration in volume and funding accentuates the need to invest in the infrastructure required to support ethical conduct of research. Only through such investments can we ensure timely improvements in health outcomes and the delivery of evidence-based services for Aboriginal and Torres Strait Islander peoples.

We do not simply need another review of ethical guidelines or processes; we need structural reform and infrastructure to the way Aboriginal and Torres Strait Islander health research upholds Aboriginal and Torres Strait Islander ethical governance. To do this, we urgently call for:

- investment to establish state-based Aboriginal and Torres Strait Islander community controlled HRECs in all states and territories located in the Aboriginal and Torres Strait Islander Community Controlled Health sector;
- increase in the current investment to Aboriginal and Torres Strait Islander community controlled HRECs, with recognition of the growth in funding and volume of Aboriginal and Torres Strait Islander health research and evaluation into the future; and
- investment in establishing a National Aboriginal and Torres Strait Islander community controlled HREC that brings together state-based Aboriginal and Torres Strait Islander community controlled HRECs to oversee multijurisdictional and national research and evaluation. This should be positioned in a national Aboriginal and Torres Strait Islander Community Controlled Health Research Organisation.

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