

Beyond ethical guidelines: upholding Aboriginal and Torres Strait Islander ethical governance in health and medical research. A scoping review

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“The gap is not a natural phenomenon. It is a direct result of the ways in which governments have used their power over many decades. In particular, it stems from a disregard for Aboriginal and Torres Strait Islander people’s knowledges and solutions.”¹

Health and medical research have the potential to inform policy and health service delivery, and in turn improve the health and wellbeing of Australia’s First Peoples. Since first contact, however, Aboriginal and Torres Strait Islander people have been subjects of health and medical research that has caused significant harm and disruption to cultural practices.² It is well established that despite being the most researched people globally, research on Aboriginal and Torres Strait Islander people has been of little benefit.^{3,4} In responding to the historical and contemporary poor health and wellbeing outcomes experienced by Aboriginal and Torres Strait Islander peoples, a number of government initiatives and policies have been implemented.⁵⁻⁷ These policies have influenced a threefold increase in investment in Aboriginal and Torres Strait Islander health and medical research over the past decade.⁸ Acknowledging the lack of benefit received by Aboriginal and Torres Strait Islander people by health and medical research, alongside a continued growth in health and medical research driven by policy, it is critical to examine how research is being conducted and, notably, how Aboriginal and Torres Strait Islander peoples are involved in and govern research practices.

In Australia, the National Health and Medical Research Council (NHMRC) is responsible for monitoring health and medical research. A number of key ethical principles and guidelines have been produced, under the precedence of the NHMRC *National statement on ethical conduct in human research* (hereafter referred to as the National Statement) — a set of responsibilities to guide research practices and processes, first established in 2007⁹ and updated in 2023.¹⁰ These documents are intended for use by researchers, institutions and ethics review bodies, including human research ethics committees (HRECs). In response to the harm caused by Euro-Western knowledge systems, Aboriginal and Torres Strait Islander peoples have concurrently led recommendations for research practice since 1987.¹¹ This has included, but is not limited to, the establishment¹² and refinement¹³ of specific values and principles that must also be applied by researchers and HRECs when working in Aboriginal and Torres Strait Islander health and medical research¹⁴⁻¹⁶ to ensure respectful, safe and ethical practices.

Despite there being almost 200 NHMRC-registered HRECs across the country that review and approve research,¹⁷ only three registered Aboriginal and Torres Strait Islander community-controlled ethics committees (AHRECs) have been established — in New South Wales, Western Australia and South Australia. AHRECs were established by Aboriginal communities to embed safe and responsive ethics research principles by implementing

Abstract

Objectives: To examine what ethics approvals are being sought for Aboriginal and Torres Strait Islander health and medical research, and to determine what proportion of this research upholds Aboriginal and Torres Strait Islander ethical governance via an Aboriginal and Torres Strait Islander community-controlled human research ethics committee (AHREC) by jurisdiction and funding body type.

Study design: Scoping review of all original, peer-reviewed health and medical literature published over a 5-year period (January 2018 to December 2022).

Data sources: Extending on a previous review, the search tool Lit.search was used to access all literature relating to Aboriginal and Torres Strait Islander health and medical research.

Results: 589 eligible publications were included from the parent review, and a further 1703 publications were identified from the updated search. A total of 945 publications were included. A substantial number of ethics approvals were obtained from government-based ethics committees (394, 41.7%). More than half of the publications reported obtaining institutional ethics approval (514, 54.4%). Less than half (400, 42.3%) reported obtaining AHREC approval. Almost one-third of publications were on research that was conducted in states or territories where there is no AHREC (334, 35.3%). Publications did not always report obtaining AHREC approvals, including in jurisdictions where one operates.

Conclusions: We found a concerning lack of Aboriginal and Torres Strait Islander ethical governance reported in health and medical research. Acknowledging that Aboriginal and Torres Strait Islander ethics guidelines and AHRECs were established due to harm caused to communities, these results suggest a high risk, with research not consistently being deemed safe, respectful and beneficial with appropriate AHREC ethics review and approval. We join calls for the establishment of AHRECs in all jurisdictions and nationally. Furthermore, we urge funding bodies and institutions to uphold requirements for Aboriginal and Torres Strait Islander ethical governance in research and funding agreements, as well as institutional policies and procedures.

approval processes within the local community context.¹⁸ As such, AHRECs serve as an important mechanism in health and medical research practice, offering expert review, consideration and approval of Aboriginal and Torres Strait Islander health and medical research through this Aboriginal and Torres Strait Islander ethical governance.^{19,20} AHRECs have specialist representation, expertise and knowledge with membership consisting of primarily Aboriginal and Torres Strait Islander people who offer collective deliberation regarding the benefit, cultural safety and reciprocal and respectful research practice proposed.²¹ As the national investment into Aboriginal and Torres Strait Islander health and medical research continues to grow,⁸ it is timely to examine research practices, including how one type of Aboriginal and Torres Strait Islander ethical governance is being upheld in the conduct of Aboriginal and Torres Strait Islander health and medical research.

In this scoping review, we explored how Aboriginal and Torres Strait Islander ethical governance is upheld in research through a review of all literature, published over a 5-year period, that relates to Aboriginal and Torres Strait Islander health and medical research. Our objectives were to examine what ethics approvals are being sought for Aboriginal and Torres Strait Islander health and medical research, and determine what proportion of research upholds Aboriginal and Torres Strait Islander ethical governance via an AHREC, by jurisdiction and funding body type.

Methods

Research team and positioning

This review was led by two Aboriginal researchers (FC and MK) throughout all stages of the research. FC, a Gomeri woman and PhD candidate, and MK, a Wiradjuri woman, have expertise in social and community services and have each worked in and experienced health and medical research from the perspectives of a Euro-Western institution and a community-controlled Aboriginal and Torres Strait Islander research institute. These unique perspectives and experiences shape the approach and values in conceptualising, conducting, analysing and interpreting the data presented in this review. Support was provided to the Aboriginal authors by two non-Indigenous researchers (KB and JB) working on the review.

Study design

The conduct and reporting of this scoping review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) statement.²² This review extends on a scoping review previously published by this research team describing the research outputs relating to Aboriginal and Torres Strait Islander health since the establishment of the Closing the Gap campaign.⁸ A systematic search of the literature was initially conducted via the Lowitja Institute website using the search tool Lit.search²³ to access all literature relating to Aboriginal and Torres Strait Islander health and medical research within the PubMed database (Box 1) for the period January 2008 to December 2020.⁸ For this scoping review, a second search using the same search strategy was undertaken in February 2023 to update the search to December 2022 inclusive.

Eligibility criteria

Publications were included if they were published between January 2018 and December 2022 inclusive, and presented original peer-reviewed health and medical research conducted with Aboriginal and Torres Strait Islander people. Case studies, comparative studies, reviews, commentaries, editorials,

conference abstracts, protocols, government reports, perspective pieces and grey literature were excluded. Publications that did not directly relate to a health outcome were also excluded, including education, training, health workforce, child protection, parenting, violence and justice publications.

Study screening and data extraction

All retrieved titles and abstracts were imported into Research Electronic Data Capture (REDCap) software (version 14). Title and abstract screening for the updated search was conducted by one author (KB) and disagreements regarding full text inclusion were discussed with two Aboriginal authors (FC and MK) until consensus was reached. Data were initially coded independently by two authors (FC and KB). To ensure consistency of coding and definitions, discussions were held with MK and JB at various intervals throughout the coding process to discuss any discrepancies, with final decisions determined by the lead researcher (MK). Each publication was then double coded by one of the Aboriginal authors (FC or MK), ensuring oversight throughout; each was read in its entirety to extract the information provided in Box 2, with particular focus on information reported in the methods, ethics approval, funding

2 Data extraction and coding details

Data extracted	Details
Article details	Year of publication was recorded.
Jurisdiction of data used	For each publication, the states and/or territories where data collection occurred was recorded (New South Wales, Victoria, Queensland, Tasmania, Australian Capital Territory, Western Australia, South Australia, Northern Territory, or national). Publications of research conducted in the Torres Strait Islands were coded as such. Publications that did not explicitly report the state where data collection was undertaken were coded as unspecified. Publications that self-identified as being national in scope, or where data collection was described as being conducted in five or more states and/or territories, were coded as national studies. Publications that stated that data collection occurred in multiple states and/or territories but fewer than five were coded for each jurisdiction.
Project funding body	The name of any organisation listed as funding the research was extracted and coded by funding body type: category 1 (eg, NHMRC, MRFF, ARC), government, university, charity funding (philanthropic), unfunded and other. Publications that did not explicitly report project funding body were coded as unspecified.
Ethics approval body	The names of all HRECs from which approval was stated to have been obtained were recorded. The 2022 NHMRC-registered HREC list ¹⁷ was used to define HREC type. HRECs were categorised as: institutional HREC, government HREC (including hospital and health departments), Aboriginal subcommittee (Northern Territory) or community-controlled Aboriginal and Torres Strait Islander HREC (New South Wales, South Australia, Western Australia). Publications that explicitly stated that no ethics approval was obtained or none was required were categorised as none. Publications that did not provide the specific name of the ethics committee that provided approval (eg, those with a statement such as "This study received ethics approval from three ethics committees") were categorised as unspecified.

ARC = Australian Research Council; HREC = human research ethics committee; MRFF = Medical Research Future Fund; NHMRC = National Health and Medical Research Council. ♦

1 Summary of search terms*

The following Lowitja pre-defined terms for "Aboriginal and Torres Strait Islander health" were used:

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(((australia[mh] OR australia*[tiab]) AND (oceanic ancestry group[mh] OR aborigin*[tiab] OR indigenous[tw])) OR (torres strait* islander*[tiab])) AND medline[sb]) OR (((au[ad] OR australia*[ad] OR australia*[tiab] OR northern territory[tiab] OR northern territory[ad] OR tasmania[tiab] OR tasmania[ad] OR new south wales[tiab] OR new south wales[ad] OR victoria[tiab] OR victoria[ad] OR queensland[tiab] OR queensland[ad]) AND (aborigin*[tiab] OR indigenous[tiab])) OR (torres strait* islander*[tiab])) NOT medline[sb]) AND English[la])
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MeSH = medical subject heading. * Terms in brackets are PubMed field codes (mh, MeSH heading; tiab, title or abstract; tw, text words; sb, subset; ad, affiliation; la, language). ♦

and acknowledgements sections of the publications (Box 2). Data coding disagreements were discussed, and final decisions were made by the senior Aboriginal author (MK).

Data analysis

Data were analysed using Stata/BE and are reported as frequencies and proportions. To understand the proportions by jurisdiction and funding body type, the following groups were made: funding bodies that were listed on the Australian Competitive Grants Register (such as NHMRC, Medical Research Future Fund and Australian Research Council) were grouped as category 1; Commonwealth and state funding from hospitals and health services (such as local area health districts and health departments) were grouped as government; and universities and research institutions were grouped as institution.

Results

In the current review, we included 589 eligible publications from the parent review, covering the period January 2018 to December 2020. A further 1703 publications were identified from the updated search, for the period January 2021 to December 2022. Following removal of duplicates and study screening, a total of 987 publications met the inclusion criteria and were included in the full text review. Following further removal of duplicates and studies that did not meet the inclusion criteria, including case studies or those not relating directly to a health outcome, a total of 945 publications were included in the current review (Box 3; Supporting Information).

Box 4 presents the numbers and proportions of publications that reported receiving ethics approval by ethics body type. Fewer

than half (400, 42.3%) of the publications reported obtaining AHREC approval. A substantial number of ethics approvals were obtained from a government-based ethics committee, inclusive of health and hospital departments (394, 41.7%) and more than half of the publications reported obtaining institutional ethics approval (514, 54.4%).

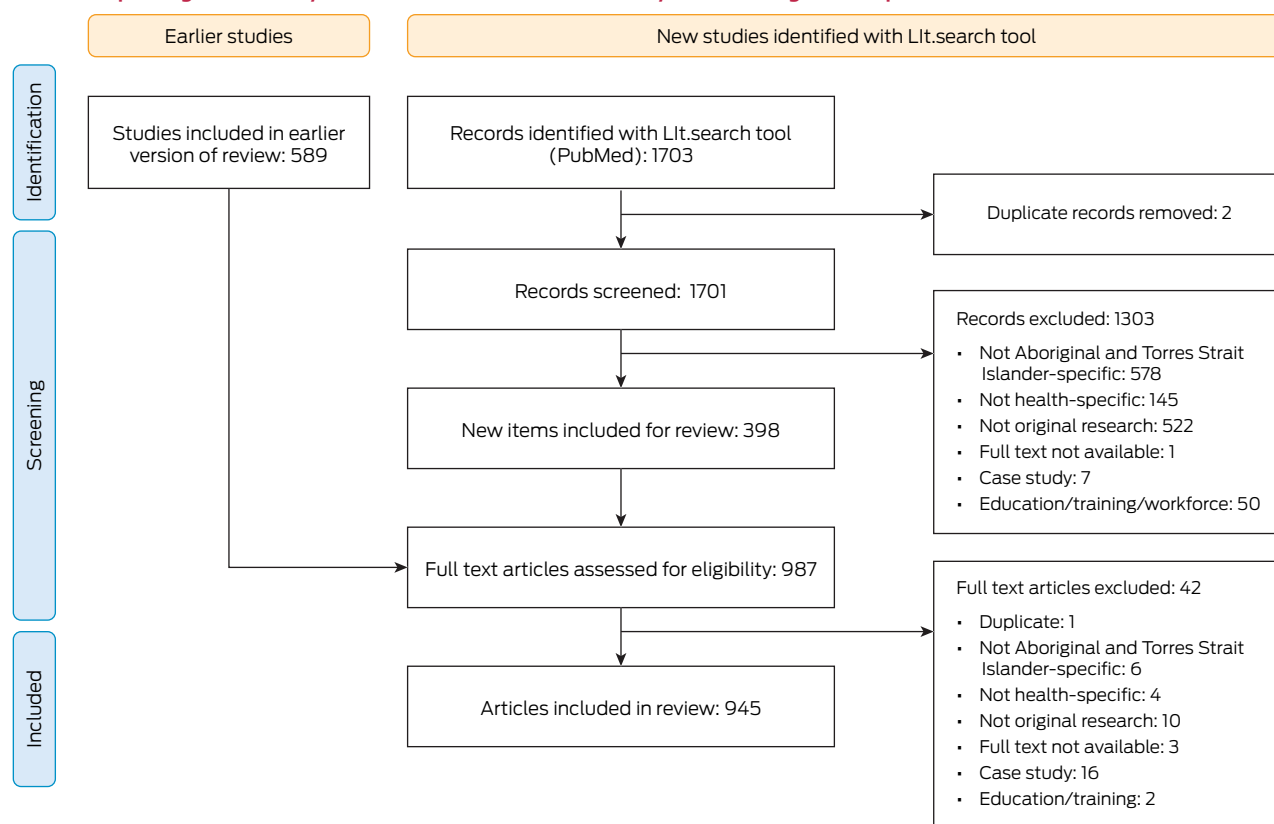
Box 5 presents the numbers and proportions of publications by jurisdiction, and those with AHREC or Aboriginal and Torres

4 Numbers and proportions of publications that reported receiving ethics approval, by ethics approval body type*

Ethics approval body type	Number
Total number of publications	945
Aboriginal and Torres Strait Islander community-controlled HREC [†]	400 (42.3%)
Aboriginal and Torres Strait Islander subcommittee [‡]	227 (24.0%)
Australian Institute of Aboriginal and Torres Strait Islander Studies	5 (0.5%)
Institution	514 (54.4%)
Government (including health and hospital departments)	394 (41.7%)
Unspecified	79 (8.4%)
Other	18 (1.9%)
None	14 (1.5%)

HREC = human research ethics committee. * Studies were coded across multiple categories if multiple funding bodies or ethics approvals were specified, therefore numbers do not add to 945. † These types of ethics approval bodies were only in New South Wales, Western Australia and South Australia. ‡ This type of ethics approval body was only in the Northern Territory. ♦

3 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of updated reviews



5 Numbers and proportions of publications by jurisdiction, and those that reported Aboriginal and Torres Strait Islander community-controlled human research ethics committee (AHREC) or subcommittee approval*

Jurisdiction	Number of publications	Number with Aboriginal and Torres Strait Islander community-controlled ethics committee or subcommittee approval
Total number of publications	945	
With an AHREC		399 (88.5%)
Western Australia	149 (15.8%)	
New South Wales	178 (18.8%)	
South Australia	124 (13.1%)	
With a subcommittee		223 (92.9%)
Northern Territory	240 (25.4%)	
Without an AHREC or subcommittee		—
Queensland	225 (23.8%)	
Victoria	48 (5.1%)	
Tasmania	6 (0.6%)	
Australian Capital Territory	6 (0.6%)	
Torres Strait Islands	20 (2.1%)	
National	121 (12.8%)	70 (57.9%)
Unspecified	29 (3.1%)	—

* Publications were coded across multiple jurisdictions if they reported on research conducted in more than one state, but not nationally, therefore numbers do not add to 945. ♦

Strait Islander subcommittee approval in jurisdictions in which such committees were operating. Most were conducted in the Northern Territory (240, 25.4%) and Queensland (225, 23.8%), together representing almost half of all research conducted in Aboriginal and Torres Strait Islander health. Almost one-third of the research was conducted in states or territories where there is no AHREC (334, 35.3%). National projects comprised 12.8% (121) of research conducted.

Box 6 presents the numbers and proportions of publications of research conducted in jurisdictions with an AHREC or Aboriginal and Torres Strait Islander subcommittee that reported obtaining AHREC or subcommittee approval, by funding body type. Publications did not consistently report obtaining Aboriginal-specific ethics approvals within these jurisdictions across the different funding types, including 70 category 1-funded projects, and 31 government-funded projects. Of those publications that did not report obtaining AHREC or subcommittee approvals, a large number reported unspecified funding (34, 30%) or no funding (13, 27%).

Discussion

To our knowledge, this scoping review is the first to examine how Aboriginal and Torres Strait Islander ethical governance is being upheld in Aboriginal and Torres Strait Islander health and medical research. We found that almost half of all Aboriginal and Torres Strait Islander health and medical research published between January 2018 and December 2022 did not report having ethics approval from an AHREC. The largest proportion of research was conducted in a jurisdiction without an AHREC. We acknowledge that the Northern Territory currently has a mechanism for subcommittee approvals that comprises a collective of Aboriginal and Torres Strait Islander people, however this is situated within an institution and does not operate in a community-controlled organisation. While we recognise that there are currently systemic barriers impacting AHREC ethical governance, including limited AHREC coverage on a jurisdictional and national level, these findings indicate that a large proportion of research may not have Aboriginal and Torres Strait Islander ethical governance, including in jurisdictions where an AHREC operates. In the absence of AHREC approval, it is unclear how the National Statement⁹ is being applied to Aboriginal and Torres Strait Islander health and medical research as determined by Aboriginal and Torres Strait Islander people.

6 Numbers and proportions of publications of research conducted in jurisdictions with an Aboriginal and Torres Strait Islander community-controlled ethics committee (AHREC) or subcommittee that reported obtaining AHREC or subcommittee approval, by funding body type

Funding body type	Total number	Publications of research conducted in jurisdictions with an AHREC or Aboriginal and Torres Strait Islander community-controlled ethics committee or subcommittee		Publications of research conducted in a jurisdiction with an AHREC*		Publications of research conducted in a jurisdiction with an Aboriginal and Torres Strait Islander subcommittee†	
		Number with AHREC and subcommittee approval	Number without AHREC and subcommittee approval	Number with AHREC approval	Number without AHREC approval	Number with subcommittee approval	Number without subcommittee approval
Category 1	390	320 (82%)	70 (18%)	216 (83%)	45 (17%)	104 (81%)	25 (19%)
Government	158	127 (80%)	31 (20%)	98 (84%)	19 (16%)	29 (71%)	12 (29%)
Institution	64	53 (83%)	11 (17%)	40 (89%)	5 (11%)	13 (68%)	6 (32%)
Charity	85	70 (82%)	15 (18%)	50 (88%)	7 (12%)	20 (71%)	8 (29%)
Other	74	63 (85%)	11 (15%)	41 (89%)	5 (11%)	22 (79%)	6 (21%)
Unspecified	113	79 (70%)	34 (30%)	56 (76%)	18 (24%)	23 (59%)	16 (41%)
Unfunded	48	35 (73%)	13 (27%)	20 (77%)	6 (23%)	15 (68%)	7 (32%)

* Included jurisdictions were New South Wales, Western Australia and South Australia. † Northern Territory was the only included jurisdiction. ♦

Acknowledging the role of research to inform policy and health service delivery, these findings raise concern that knowledges informing policy may not align with Aboriginal and Torres Strait Islander priorities and governance processes as there is no evidence that Aboriginal and Torres Strait Islander people have reviewed, deliberated or approved the research. It is well established that Aboriginal and Torres Strait Islander people are best placed to interpret and apply the National Statement⁹ and ethical guidelines^{14,15} to ensure that research conducted is safe and of benefit to Aboriginal and Torres Strait Islander people participating in the research.²⁴ One such mechanism to support Aboriginal and Torres Strait Islander ethical governance of research is AHRECs. AHRECs offer external expert review, assessment and approval of research that mitigate institutional biases by a collective of Aboriginal and Torres Strait Islander people. While obtaining AHREC review is not mandatory in any current ethics guidelines, the National Statement acknowledges that “The message for researchers is that there is great diversity across the many Aboriginal and Torres Strait Islander cultures and societies. Application of these core values, and of additional cultural and local-language protocols, should be determined by the Aboriginal and Torres Strait Islander communities or groups involved in the research.”⁹

Aligned with the National Statement, AHRECs provide a mechanism for Aboriginal and Torres Strait Islander ethical governance determining how and what research is conducted with Aboriginal and Torres Strait Islander people and communities. Despite their pivotal role, we found that one-third of research is being conducted in states and territories without an AHREC, and that only 57.9% of national research reportedly obtained approval from an AHREC despite the likelihood of the research being conducted in at least one state or territory with an AHREC. These findings are concerning given the need for national level evidence to drive policy change²⁵ and the complex nature of multijurisdictional and national research requiring appropriate deliberations to apply the National Statement and ethics guidelines. Other researchers have reported the complexities of obtaining ethics approvals for national studies as a barrier to conducting Aboriginal and Torres Strait Islander health research.²⁶ Acknowledging these complexities, it remains imperative that AHREC approval is sought and reported to ensure that researchers are appropriately applying ethics guidelines as determined by Aboriginal and Torres Strait Islander people to reduce the risk of further harm that national and multijurisdictional research has the potential to cause.

While the current landscape of Aboriginal and Torres Strait Islander ethical governance poses systematic barriers such as a lack of national coverage, Aboriginal and Torres Strait Islander communities continue to lead the work required to uphold Aboriginal and Torres Strait Islander ethical governance. Funded by the Lowitja Institute, the Victorian Aboriginal Community Controlled Health Organisation and the Queensland Aboriginal and Islander Health Council are currently undertaking feasibility studies and consultations to establish AHRECs, and the Victorian Aboriginal Community Controlled Health Organisation has recently published their accord.²⁷ Further, the Medical Research Future Fund has funded the critical work for the Lowitja Institute to establish a national AHREC.^{28,29} However, state and territory governments will be required to work with peak bodies in the Aboriginal and Torres Strait Islander community-controlled sector to establish and maintain appropriate AHRECs including identifying sustainable funding mechanisms. While these developments are promising, there must be simultaneous mechanisms in place to ensure that

appropriate ethics approvals are sought and reported on by funding bodies, researchers, institutions and journals, including ethical reporting and accountability.³⁰

In our study, we found that Aboriginal and Torres Strait Islander ethical governance via an AHREC was consistently not upheld, including in jurisdictions where one operates. With the implementation of priority and target funding schemes, the volume of research being conducted is likely to continue to increase. While increased investment in Aboriginal and Torres Strait Islander health research is welcomed,³¹ the National Statement must be adhered to in full, which includes upholding the rights of Aboriginal and Torres Strait Islander people. We urge funding bodies to consider their responsibilities in ensuring that Aboriginal and Torres Strait Islander ethical governance is being upheld, including AHREC approval, before funds are released. Acknowledging that research is also being conducted without funding, researchers and their institutions as well as non-Aboriginal and Torres Strait Islander ethics committees must take responsibility to ensure that Aboriginal and Torres Strait Islander ethical governance is upheld in all research conducted regardless of the size and scope of the project.

Aboriginal and Torres Strait Islander ethical guidelines were developed by and for Aboriginal and Torres Strait Islander people and communities as a protective measure, acknowledging the historical harms caused and the continued risk and harm that research has the potential to cause. Without appropriate reporting and utilisation of AHRECs, we are unable to conclude that current research in Aboriginal and Torres Strait Islander health is consistently safe and beneficial from the perspective of Aboriginal and Torres Strait Islander people. Researchers must seek AHREC approvals for research conducted in states where there is an operational AHREC. Upholding Aboriginal and Torres Strait Islander ethical governance is the shared responsibility of researchers, funding bodies, and institutions, who are required to consider their role in ensuring that mechanisms of accountability are embedded to uphold this ethical governance, to ensure that health and medical research is safe and beneficial to Aboriginal and Torres Strait Islander people.

Limitations

This review could only examine published literature in which the researchers have appropriately reported on ethics approval and funding bodies, and we acknowledge that researchers might have experienced limitations by journal publishing practices excluding the relevant details for this review. Another limitation of our study is that not all researchers specifically reported obtaining ethics approval from the Aboriginal Ethics Sub-Committee in the Northern Territory, however studies were coded as having received approval from the subcommittee given the likelihood that this was part of the standard process of the combined NT Department of Health and Menzies School of Medical Research human research ethics committee.

Conclusion

AHRECs are an important mechanism for upholding Aboriginal and Torres Strait Islander ethical governance of research that aims to improve the health and wellbeing of Aboriginal and Torres Strait Islander people. We found that Aboriginal and Torres Strait Islander ethical governance is not being consistently upheld via AHREC approval, even in jurisdictions where one operates. Acknowledging that Aboriginal and Torres Strait Islander research ethics guidelines were established due to harm

caused to Aboriginal and Torres Strait Islander peoples, these results suggest that there is a high risk associated with current research practice. Research is not consistently being deemed safe, respectful and beneficial for Aboriginal and Torres Strait Islander people by appropriate AHREC review and approval. Researchers, funding bodies, institutions and journals share collective responsibility to ensure that all research conducted with Aboriginal and Torres Strait Islander people has justifiable benefit and impact for our health and wellbeing outcomes. We join calls for the establishment of an AHREC in all jurisdictions and nationally. Furthermore, we urge funding bodies and institutions to uphold the requirements for Aboriginal and Torres Strait Islander ethical governance to be embedded

within policies and practices in a shared commitment to the responsibilities outlined in the National Statement to ensure that research is deemed safe, respectful and beneficial by and for Aboriginal and Torres Strait Islander peoples.

Acknowledgements: We acknowledge that this research was conducted across unceded lands of Aboriginal and Torres Strait Islander peoples and pay respect to the elders and caretakers of the lands, seas, sky and waterways. We acknowledge that Aboriginal and Torres Strait Islander peoples are the knowledge holders and pay respect to their wisdom and processes for knowledge productions and knowledge sharing.

Competing interests: No relevant disclosures. ■

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Supporting Information

Additional Supporting Information is included with the online version of this article.