



Supporting Information

Supplementary methods and results

**This appendix was part of the submitted manuscript and has been peer reviewed.
It is posted as supplied by the authors.**

Appendix to: Kennedy M, Booth K, Bryant J, et al. Human research ethics committee processes and practices for approving Aboriginal and Torres Strait Islander health research: a mixed methods study. *Med J Aust* 2025; doi: 10.5694/mja2.52563.

Box 1. Survey items

The final survey included 36-items with questions about respondent demographics (age, gender, Indigenous status) and Human Research Ethics Committee characteristics (state/territory of committee, remunerated position, ethics committee type). Further questions about Human Research Ethics Committee processes included Aboriginal and/or Torres Strait Islander representative position (*yes, no, don't know*), if it is currently filled (*yes, no, don't know*), ratification of Aboriginal Human Research Ethics Committee approval (*yes, no, don't know*); Aboriginal-specific review/approval of research on the general population where Aboriginal and Torres Strait Islander people are likely to be part of the sample (*never, sometimes, often, always, don't know*). Committee provided training to (a) Human Research Ethics Committee members and (b) researchers about Aboriginal and Torres Strait Islander health research, and whether the committee recommends any training (*yes, no, don't know*). Number of applications received annually (*sliding scale from 0 to 100+*), perceptions of how manageable applications are to review (5-point Likert scale, *not at all manageable to completely manageable*), quality of applications (5-point Likert scale, *very poor to very good*), most common initial outcome (*approved first time with no amendments, approved with minor amendments, major amendments required, rejected*), and the average number of reviews per application prior to approval (*sliding scale from 0 to 10+*). Key issues identified during ethical review that researchers most often require additional assistance/amendments before receiving approval.

Table 1. Illustrative quotes

Reported HREC membership structure	
Theme 1: Despite being seen as crucial in providing oversight, there was not often an Aboriginal representative on HRECs	
HREC members perceive having Aboriginal representation on the committees to be crucial in providing oversight on applications.	<p>"I think it's a really important process. It's a structure that is in place that ensures on some level there is a more appropriate review mechanism." — P2, non-Indigenous</p> <p>"A couple of years ago we had a really brilliant Indigenous, a fella by the name of ... And [he] would, obviously, come to the meetings and provide input onto those specific applications. But he'd come to the entire meeting and provide that same level of insight into all the applications. And I reckon having that perspective made the discussions and all the decisions much better ..." — P3, non-Indigenous</p> <p>"At the moment we're second guessing some stuff. We don't make any decisions when it comes to Aboriginal and Torres Strait Islander peoples or health. But it would be good to have someone in the room when we're making general comments ... I think it would be useful to have Aboriginal and Torres Strait Islander perspectives on our committee, to make sure that our communications back to researchers and with the AH&MRC [are] culturally safe. I think that there would be great value in that." — P4, non-Indigenous</p> <p>"More practically, when we did have [an Indigenous representative] on the committee, he would point out stuff that we just didn't see ... But he would point out when things were innately disrespectful or that there were presumptions made about the way the world is that, once again, we learnt something every meeting we had him there. It was so fantastic." — P6, non-Indigenous</p>
The Aboriginal and Torres Strait Islander role was not always filled, even if the HREC had a dedicated position.	<p>"I wouldn't call it casual, but it's definitely ad hoc. The two people who are First Nations people have other areas of expertise, so they're mainly lay community members. One of them is actually a chaplain, so that counts." — P1, non-Indigenous</p> <p>"So, we actually have a fulltime position, an absolute fulltime position. Our problem is filling that fulltime position." — P3, non-Indigenous</p> <p>"Although I tried to have a standing member on the committee and it's proved very difficult, actually, because it's my view that it's not just Aboriginal and Torres Strait Islander research itself that needs to have First Nations input. It's all research." — P6, non-Indigenous</p> <p>"I think we would love a position on the committee to be an Aboriginal or Torres Strait Islander person, as a role on the committee. I think mandating that would be tricky because then you're making these people sort of ... Or committee can't function without somebody, and it may just not be feasible. I mean there are a lot of great Aboriginal researchers out there that we know. So, it's not a question of 'aren't there enough?', it's a question of 'do they have time in their lives, do they even want to do this?'. So that would be great to have maybe even just not a mandatory role, but that'd be awesome ... — P7, non-Indigenous</p>
The struggle to fill the position was attributed to perceptions of existing burden on Aboriginal and Torres Strait Islander people, disenfranchisement with academia and research, as well as limited remuneration opportunities for the role. One participant stated that they have raised the issue with the chair, who has not progressed it further.	<p>"Well, I think you're an academic, in which case you're overworked, because that's what academia is like. And ... Indigenous academics, if anything, have just got more weight of expectations on them than everyone else. So that's one way. And then you're getting paid, otherwise you're on the committee and you're not an academic and you're basically not getting paid." — P5, non-Indigenous</p> <p>"I think it's an issue about how every Aboriginal academic or researcher is completely overwhelmed with work and with other kinds of obligations." — P6, non-Indigenous</p> <p>"We've tried to get it but we can't get anybody. I interviewed, along with the coordinator, a person last year who would've been ideal but it all fell through. So, we're pretty keen to do that. I guess, it's always the problem, actually, is that there's not enough people to go around. So, everybody's asking for their input and that makes it a bit difficult, I think." — P9, non-Indigenous</p> <p>"It's a relatively small pool of people, so the reason ... As far as I know, the reason it's not filled is just time pressures on the academics. So, they don't have time to come to the meetings." — P8, non-Indigenous</p> <p>"It has come up in discussion. And it hasn't been taken further by the chair." — P4, non-Indigenous</p>

When unable to fill this role, committees would sometimes seek external consultation, such as hospital staff or university-based Indigenous groups.

One mentioned having a non-Indigenous representative for Indigenous research.

“And we also have a new excellent First Nations staff member at the hospital who we consult with quite a bit.” — P1, non-Indigenous

“We do have an Indigenous research group within the university and getting representatives for the committee is very difficult. And they will, as a general rule, they will come to a meeting for that particular application and they will go. Which, I reckon, it’s to the detriment of the committee.” — P3, non-Indigenous

“Yes, it’s currently not filled and hasn’t been filled for quite some time. What happens with Aboriginal and Indigenous topics is that there is an Indigenous reviewer, who is usually internal to the university but sometimes external to the university, but there is always at least one Indigenous [reviewer] for any Indigenous project.” — P8, non-Indigenous

“The chair works with the Indigenous group. At the moment our representative from that group is, in fact, not Indigenous but is part of that group and she’ll come to every meeting in which there is an Indigenous application. And will, usually, stay for the entire meeting but unless there’s one of those she will not come.” — P3, non-Indigenous

Reported review, approval and monitoring processes/procedures

Theme 2: AHREC approvals and administrative control improve the quality of applications

Many of the Aboriginal and Torres Strait Islander research applications are required to have approvals from state-based Aboriginal-specific ethics committees (eg, AH&MRC) or community consultation before they are accepted for review.

“So, we make sure that at least they’ve consulted with the AH&MRC as well, if that’s a requirement. And we had one recently that was really well done.” — P7, non-Indigenous

“Should they wish to report on Aboriginal or Torres Strait Islander people, that then our approval is conditional on them going to, in our state, the AH&MRC for approval.” — P4, non-Indigenous

“What we expect before that the application comes to us that that’s actually been through the local community representatives. And there is actually a committee that sits in the health department, we expect it to have gone through there first. There’s no point us discussing it if the community aren’t happy.” — P9, non-Indigenous

One participant recognised the burden that AHREC pre-approval requirements may place on Aboriginal-specific ethics committees.

“And [the AH&MRC] might end up suddenly being completely overloaded because these two assets are amazing in their breadth and depth but must have that Indigenous oversight and approval mechanism. Because it’s currently not offered by ABS or AIHW ... So, how much training, exposure, expertise will the AIATSIS members have to be able to pick up the load that’s coming their way?” — P4, non-Indigenous

Applications were reviewed by the secretary or administrative staff, so only those of required standard would reach the committee for review.

“So, the research office, they have a whole process of going through all the applications. So they’re all reviewed according to administrative requirements as well. So if they’re missing a protocol or vital parts there’ll be emails back and forth. So there’s a lot of work done in the background before it comes to us as a committee to make sure everything’s together, everything’s been submitted properly.” — P7, non-Indigenous

Theme 3: There are not always clear processes for reviewing, approving and monitoring research

It was not always clear if an application should be considered general population or Aboriginal specific.

“And then there are projects that want to do the whole of population and use the Indigenous identifier as a covariable. And there’s been a longstanding agreement between our committee and AH&MRC that that is okay and doesn’t have to go to AH&MRC because of the burden on them and the researchers would just be too great ... It would probably be worth revisiting that one in light of greater awareness of Indigenous data sovereignty, Indigenous data governance. It’s almost like no one wants to touch the system because it currently seems to be working from the perspective of our committee, not necessarily Indigenous communities.” — P4, non-Indigenous

“I can’t remember all the ways that we decided this, but there’s certainly times when we would say, okay, it’s not some Indigenous research because you’re not asking any questions specifically about Indigenous people or whatever. I think that’s a very tricky issue that needs a good answer.” — P5, non-Indigenous

“I think we only ever get studies that will incidentally recruit people who identify as Aboriginal or Torres Strait Islander. So it will just be part of their big cross-section or catchment. Or we get studies that specifically target that population. So it’s up to the study, but the NHMRC have in our standards for ethical review, specific boxes that we check if there are populations being targeted. It’s just like pregnant women, it’s the same thing. So we have to take it up a notch according to the standards if they’re targeting a certain population.” — P7, non-Indigenous

“Or people might say they are not planning to look at an Indigenous aspect. So, they might be looking for a big dataset. And it might be relevant, you could argue that there’s a relevance specifically or importantly to an Indigenous area but they’re not planning to look at it. And so, commonly, we ask the question ‘well, why not?’ And, again, that’s not our ... We don’t have control over that. It’s up to the researchers to decide what they want to look at or not.” — P11, non-Indigenous

Sometimes the chair is responsible for deciding if the research constitutes as general population or requires Aboriginal-specific approvals.

One HREC member stated that their committee had rejected an application for a project involving Aboriginal and Torres Strait Islander research. Another committee then approved the research without making changes that they deemed would be needed to be ethical. The HREC member suggested that researchers are “shopping around”, which is unregulated, and the complaint process had not been managed.

Another participant mentioned that if an application has already been approved from another committee, that it will be approved without revision from their committee.

It was suggested that standardising ethics structures would help to omit some of these issues, especially as the NHMRC guidelines are open to a level of interpretation.

“Previously, we had been working on the basis that because it was in [the high risk] designation, it had to go to the full committee. But that’s actually my call. So, the chairs are a lot more powerful than they know they are.” — P6, non-Indigenous

“We’ve had projects where it’s been the general population and there may be some Indigenous participants. But the general feeling of the chair is that unless it’s research focused on Indigenous participants and Indigenous issues, then it just goes to the general pool of how we discuss them.” — P8, non-Indigenous

“If an ethics committee denies approval to an application, and those applicants aren’t strictly local but are regional or national, they can go to another ethics committee and gain approval. And there’s no mechanism in place now at the national level or any level below that to adjudicate the difference between those two views of an application.” — P1, non-Indigenous

“Well, we don’t really know because you go through some review and then you approve a thing and then they go off and do it. And they report back to the chair or the ethics office and they have an annual, whatever, review. But the committee never looks at that. The committee definitely never sees the publication that they write 3 years later. So there’s no feedback loop in that way of knowing whether, like we were worried about A, B and C. Did any of those things happen? We’ll never find out.” — P5, non-Indigenous

“It doesn’t go to committee. So, if it’s been approved by another university, it just goes to the chair. The chair ticks it off and it’s mirrored with the presumption that everybody else’s ethics committees work well under the national statements. So, that’s the same with projects that have gone through hospitals as well.” — P8, non-Indigenous

“And how quickly and how stringently you apply different aspects of the NHMRC guidelines, I guess, is the nuances of each different ethics committee as you interact with them ...” — P10, non-Indigenous

“... that’s the foundation. That you have really standardised, protocolised, national ethics process and then, once you’ve got the backbone of that really strong then you can plug into it like your region-specific committees and recruit the right skills and representation into that.” — P2, non-Indigenous

Review and approval operations

Theme 4: The workload to review Aboriginal and Torres Strait Islander applications falls on Indigenous members

Non-Indigenous respondents sometimes found the amount of applications manageable as there was flexibility in what they were able to take on.

However, some were mindful of calling on Indigenous researchers too much for advice on Aboriginal and Torres Strait Islander-specific applications.

Aboriginal members noted that there were at times issues of cultural burden and expectations to speak on behalf of other Indigenous people, as well as having a higher load of applications to work through.

“But in my circumstance, just with work and stuff, I have a desire to participate and the way in which I can participate is in that more remote capacity. It’s not been formally agreed with the committee, it’s just that I’m like, I can’t make it this week, here’s my notes.” — P2, non-Indigenous

“Yes, for the committee members it’s fine, we signed up for this, we’re volunteers. So, if the workload’s too much you just stop volunteering and you have to withdraw from the committee.” — P7, non-Indigenous

“It’s not a huge work volume committee, and that generally works okay.” — P8, non-Indigenous

“It’s manageable. We’re expected to spend about a day in preparation and that’s, probably, about right. And then there’s a full day of the committee.” — P11, non-Indigenous

“One of the stressors is when we do get First Nations-oriented research we do like to tap one of these two people, so we worry from time to time that we’re calling on them too often. They’ve expressed comfort and said that’s fine, keep it up, but we don’t want to overtax them, and we sometimes feel like we’re doing so.” — P1, non-Indigenous

“So, we’re just speaking from a non-Indigenous only perspective when we do that. I think it would be helpful, but we are cognisant of the fact that there’s not many Indigenous health researchers. And they’re pulled in 50 different directions. And I don’t know if our committee has approached people or not. I honestly can’t remember. But we do discuss it from time to time.” — P4, non-Indigenous

“And then that leads to that cultural burden and that knowledge drain. That they think because you’re Aboriginal you know everything about every blackfella in Australia. No I don’t. And I don’t ever want to pretend to be that person either.” — P13, Aboriginal

“Because most people tick ‘yes it’s going to have Aboriginal and Torres Strait Islander people’ so sometimes I could be reviewing four or five applications at a meeting. There’s not enough of us as black academics to be able to do these things.” — P13, Aboriginal

Theme 5: The quality of applications influences the ability to manage workload and time spent on review

<p>Participants noted that high quality applications were easier to manage and reduced time spent on review.</p>	<p>“Applications that are well written are just so much faster than applications that are a mess.” — P5, non-Indigenous</p> <p>“I think the applications we get are very good. So, they’re of a very high standard and that’s very pleasing to me. So, they generally fly through.” — P6, non-Indigenous</p> <p>“If somebody had a significant Aboriginal focus and they hadn’t put the appropriate consultations into place, then the request, probably, wouldn’t get to us in the first place.” — P11, non-Indigenous</p>
<p>One of the first things that reviewers look for in quality applications is efficient consultation and engagement with Aboriginal and Torres Strait Islander people through all stages of the research and Aboriginal leadership.</p>	<p>“There’s been a couple of applications that are specifically focused on Aboriginal participants or Aboriginal researchers. And it was really interesting that in one of them in particular there was, obviously, no community engagement prior to setting up that project. Or there, certainly, wasn’t any real evidence that that had been done in a respectful way.” — P10, non-Indigenous</p> <p>“The ones we get from the Indigenous scholars are usually actually pretty good. The amendments are generally fairly minor. The main time we get big problems is when people want to do an Indigenous topic and they actually haven’t engaged with the Indigenous unit at all, and then there’s usually big problems, yes.” — P8, non-Indigenous</p>
<p>One member emphasised that without engagement and agreement, the research would not occur, and was therefore a waste of time.</p>	<p>“And then the forms, only if they’re actually really concentrating on Indigenous people, then they’ve got an agreement ... Mainly it’s to ensure they get engagement, that they’re getting others. Otherwise they’re going to do the research, anyway, waste their time.” — P13, Aboriginal</p>
<p>One Aboriginal HREC member mentioned the frustrations of being asked to assist in research projects (ie, with recruitment) because the non-Indigenous researcher had not appropriately engaged the community.</p>	<p>“I’m really sick of reading ethics applications when they say, I’m going to contact my Aboriginal friends to recruit people. That’s cultural burden on your friends who will probably not be your friends if you keep doing that sort of stuff to them. If you can’t engage with community adequately before you decide what you’re going to do, I’m sorry I don’t think you should be putting in ethics.” — P13, Aboriginal</p> <p>“We have this Western framework, we have this budget stream, we have this funding stream, we have this funding window. And that’s why I say when people are thinking about researching in this space you need to start engaging before you even start to apply for grants. So that you know that if you are successful you’ve already got engagement with that community who’ve gone ‘yes we want to be part of this’.” — P13, Aboriginal</p>
<p>This included relationships beyond just researcher and study participant.</p>	<p>“I had 200 children on my study. I probably can’t do it now but back then someone could say a number and I could give you the name of that participant. To me they weren’t a number. They were a family and a child. So you could say number one and I could say that’s so-and-so. And they would say how do you do that? And I’d say I’m spending time with these families. I’ve got to know them. I’m following them around for the next 12 months of their life. I contact them all the time so to me they are not just a study number they’re a person.” — P13, Aboriginal</p>

ABS = Australian Bureau of Statistics. AH&MRC = Aboriginal Health and Medical Research Council. AIATSIS = Australian Institute of Aboriginal and Torres Strait Islander Studies. AIHW = Australian Institute of Health and Welfare. HREC = human research ethics committee. NHMRC = National Health and Medical Research Council.

CONSolidated critERia for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) statement

<p>Governance</p>
<p>This research engages multiple levels of Aboriginal and Torres Strait Islander governance. Formal governance was enacted by the National Indigenous Health Leadership Alliance (NIHLA – formerly National Health Leadership Forum) which comprises of representatives from Aboriginal and Torres Strait Islander organisations and peak bodies committed to systemic and structural reform. The NIHLA has provided governance and oversight across all aspects of the research, guiding and strengthening the research by ensuring it is safe, impactful and upholds prioritisation of need and benefit for Aboriginal and Torres Strait Islander communities. The lead researcher (MK) met with the NIHLA at least bi-annually throughout the development, implementation, interpretation and dissemination of the research to ensure tangible and efficient practice and policy changes were made. The research, as led by a collective of Aboriginal and Torres Strait Islander researchers, uphold governance and oversight of all aspects of the work. All required ethical approvals were obtained, including from the Australian Institute of Aboriginal and Torres Strait Islander Studies (HREC reference no. EO323-20220414) and the Aboriginal Health & Medical Research Council (HREC reference no. 1924/22).</p>
<p>Prioritisation</p>
<p>This research emerged from the priorities of Aboriginal and Torres Strait Islander people and communities for truth telling and critical reflection of the field of ethics in health and medical research. As such, pre-existing, alongside new community partnerships have been established throughout the research to ensure the research continues to uphold the priorities and voice of Aboriginal and Torres Strait Islander people. The governance processes within this research ensure rapid translation of findings into policy and practice to meet the identified community priorities.</p>
<p>Relationships</p>
<p>This work upholds Aboriginal and Torres Strait Islander peoples rights to self-determination, leadership and decision-making throughout all stages of the research in line with the principles of the United Nations Declaration on the Rights of Indigenous People (UNDRIP) and ethical principles of Aboriginal and Torres Strait Islander health and medical research. Relationality to the work, communities and between the researchers has been pivotal to ensure the research safeguards Aboriginal and Torres Strait Islander people and communities throughout the development, implementation, interpretation and translation of this project. This responsibility and accountability to the improvement of health and wellbeing outcomes for Aboriginal and Torres Strait Islander people extends beyond the life of the project to ensure the researchers remained responsive to the evolving and changing needs and priorities of communities. Acknowledging that Aboriginal and Torres Strait Islander people are not homogenous and are a diverse people, the research team brought decades of experience and expertise across a range of settings and locations to ensure the research considered, and was appropriate, across and between communities and their contexts nationally.</p>
<p>Methodologies</p>
<p>This research has been led and implemented by Aboriginal and Torres Strait Islander experts and leaders across a range of disciplines in health and medical research. Indigenous worldviews and relationality,</p>

underpinned by Indigenist research methodologies ensure the research is transparent and accountable to Aboriginal and Torres Strait Islander communities. As Aboriginal and Torres Strait Islander people and researchers, the concept of ethical practice is not new. The ways in which this research is conducted is deeply rooted in our lived experiences and realities, including the complexities of upholding relational research practices within Euro-Western systems. Consequently, this intrinsically influences how this research has been shaped, interpreted and translated, upholding Aboriginal and Torres Strait Islander rights to ethical research and outcomes.

Participation

This study sought to understand the experiences and perspectives of a diverse range of participants conducting health and medical research with Aboriginal and Torres Strait Islander people and their data. This included from Aboriginal and Torres Strait Islander communities, researchers and human research ethics committee members. The seeking of individual and community consent was imperative to mitigate burden placed on participants, particularly any Aboriginal and Torres Strait Islander people or communities. Indigenous data sovereignty principles were upheld to ensure the safety and security of all participants throughout the research. All data has been presented as deidentified to protect participants and communities.

Capacity

The *Murru Minya* project supports Aboriginal and Torres Strait Islander research capacity through the development and mentorship of an Aboriginal PhD Candidate and an Aboriginal community researcher. The guidance and leadership of the extensive Aboriginal and Torres Strait Islander research team has been woven throughout all stages of the research. Through respectful and reciprocal relationships, this research has engaged with key stakeholders within the Aboriginal and Torres Strait Islander community-controlled sector and other research institutes to build capacity within the sector across a range of areas including research design, implementation and knowledge translation.

Analysis and interpretation

Collaborative Yarning between the Aboriginal and Torres Strait Islander researchers was pivotal to the analysis process which prompted reflexive analysis and sense-making of the data. Drawing on our own lived experiences as described by Tuwahi-Smith, the research team have become deeply interconnected with the data as both the researched and researcher. Grounded in our standpoint, Nakata describes this *“is a distinct form of analysis and is itself both a discursive construction and an intellectual device to persuade others and elevate what might not have been a focus of attention by others”*. Consequently, this uniquely influences and shapes the ways in which the data in this research have been analysed and interpreted. Through an exploration of the field of Aboriginal and Torres Strait Islander health and medical research, by Aboriginal and Torres Strait Islander researchers, this work re-positions Euro-Western standard practices of research whereby the predominantly non-Indigenous researchers and research systems are the subjects of Indigenous research as defined by us.

Dissemination

Rapid knowledge translation and dissemination of findings from this study have been interwoven and in-process prior to publication of this work. During project implementation, ongoing knowledge translation to project governance and leaders occurred, and a website was created with a focus on community-level translation in real-time. Through the website, members of the academic sector and community were able to

register to receive regular newsletters and project updates. Prior to submitting manuscripts, in-process findings of this study were shared with the research governing body and the Aboriginal Health & Medical Research Council Ethics Committee. A series of personal invitations, locally and nationally, were received to present to community organisations and research institutes. This has included presentations to the Wakul Yabung Aboriginal Health Research Panel at the University of Newcastle (NSW), Wardliparingga Aboriginal Health Equity Unit at the South Australian Health and Medical Research Institute (SA) and Telethon Kids Institute (WA). Key international presentations have included the Lowitja Institute International Indigenous Health Conference (2024), World Indigenous Cancer Conference (2024) and an International Knowledge Exchange Event held with Indigenous colleagues from the British Columbia Network Environment for Indigenous Health Research, Canada (2024). A 16-page knowledge translation booklet has been developed to share findings with key stakeholders and communities in the sector.