



Human research ethics committee processes and practices for approving Aboriginal and Torres Strait Islander health research: a mixed methods study

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The known: Aboriginal and Torres Strait Islander health and medical research must be conducted in accordance with specific ethical frameworks and guidelines to ensure that the rights and perspectives of communities are upheld.

The new: Aboriginal and Torres Strait Islander people are under-represented in ethics review and monitoring of Aboriginal and Torres Strait Islander health research. Current HREC structures, processes and operations do not consistently uphold Aboriginal and Torres Strait Islander rights and expert knowledges.

The implications: This research identifies the need for a coherent ethics process, standardised guidelines, and an NHMRC-endorsed monitoring and reporting process for all Aboriginal and Torres Strait Islander health research.

Human research ethics committees (HRECs) receive, review and monitor approved research. In Australia, HRECs must be registered with the National Health and Medical Research Council (NHMRC). In 2021, there were 189 registered HRECs within universities, government and non-government departments, and private organisations.¹ Of those, three were identified as Aboriginal HRECs (AHRECs), which are community-controlled and have specialist expertise in reviewing research involving Aboriginal and Torres Strait Islander people. All registered committees must abide by specific rules about membership, roles and responsibilities of members, processes used in assessments, and requirements for annual reporting to the NHMRC that have been established in line with ethical frameworks and guidelines.²⁻⁷

The NHMRC releases annual reports on the activity of HRECs detailing attributes including: composition; processes for reviewing, reporting and monitoring; and mechanisms for handling complaints.¹ The 2021 report noted that half of registered HRECs considered research proposals relating to Aboriginal and Torres Strait Islander people and 73% of proposals underwent a standard review process within the HREC, with some HRECs also identifying use of invited experts or referral to a specialist HREC, subcommittee or external advisory group.¹ However, there are no reported data related to the processes used by HRECs to review, approve and monitor Aboriginal and Torres Strait Islander health research or their structures and processes.

To uphold ethical frameworks, guidelines and practices, it is critical to understand how Aboriginal and Torres Strait Islander

Abstract

Objectives: To describe human research ethics committee (HREC) members' reports of: HREC membership structures; HREC processes for reviewing Aboriginal and Torres Strait Islander health and medical research; and experiences and perceptions of review operations.

Study design: Cross-sectional 36-item survey and qualitative interviews with a subsample of survey participants.

Setting, participants: Current and past members (preceding five years) of HRECs who assessed Aboriginal and Torres Strait Islander research.

Main outcomes: Survey and interview results related to HREC structures, processes and functioning; challenges in review processes; and what is needed to improve ethical governance.

Results: 229 HREC members completed the survey and 13 were interviewed. Half the participants (115 of 221, 52%) reported having an Aboriginal and Torres Strait Islander representative position. Key issues identified related to assessment processes and resourcing, including burden on Aboriginal and Torres Strait Islander members, ability for Aboriginal and Torres Strait Islander HRECs to manage additional applications, lack of clarity around specific assessment criteria for general population studies, lack of cohesion across the application or complaints processes, and lack of resourcing and infrastructure to monitor ethical practice after approval.

Conclusion: Aboriginal and Torres Strait Islander people carry an important role and burden in the review of applications and monitoring of health research. However, Aboriginal and Torres Strait Islander people are not presently involved in all aspects of ethical research governance within current HREC structures, including the review and monitoring of approved research. Standardised processes and guidelines that uphold Aboriginal and Torres Strait Islander rights and expert knowledges are required.

health research is being governed by HRECs. In this article, we examine HREC members' reports of the structure, processes and operations used for reviewing and monitoring Aboriginal and Torres Strait Islander health and medical research, as well as recommendations to improve ethical governance.

Methods

Positionality

The concept of ethical practice is not new to Aboriginal and Torres Strait Islander peoples. Our ways of being incorporate praxis of ethics which connect to our relational worldview.⁸ We acknowledge that the ways in which this research is conducted

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is deeply rooted in our lived experience and relationality. Consequently, this intrinsically influences how Aboriginal and Torres Strait Islander people have engaged in the Murru Minya study. This work is conducted in line with Rigney's Indigenist methodology and aims "to delegitimize racist oppression in research and shift to a more empowering and self-determining outcome"⁹ through an exploration of the ways in which research is conducted, as examined by a collective of Aboriginal and Torres Strait Islander researchers.

The study was conceptualised and led by MK (Wiradjuri woman), in partnership with other Aboriginal (FC, CC, KEG, MW, PO, AB, SJE, KK, RL) and Torres Strait Islander (JH) researchers, supported by non-Indigenous researchers (KB, JB, RM, BH) located across these ancestral lands and geographies. Researchers are situated in a range of settings including academic and research institutions, community-controlled and clinical settings. As such, we understand the duality and complexity of upholding relational research practices within Euro-Western structures.

This work is grounded in our standpoint which, as described by Nakata "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".¹⁰ 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 repositions Euro-Western standard practices of research¹¹ whereby the predominately non-Indigenous researchers are the subjects to Indigenous research as defined by us.

Study design

A cross-sectional survey and qualitative interviews, targeting current and past members (within the previous 5 years) of an NHMRC-registered HREC involved in the process of approving Aboriginal and Torres Strait Islander research, were conducted. All 189 NHMRC-registered HRECs were emailed between September 2022 and December 2022, with a request to forward to individual committee members. At the end of the survey, participants could indicate interest in an interview. Those who indicated interest were emailed a participant information statement and consent form. While a formal a priori sample size calculation was not conducted, it was anticipated that a minimum of 200 responses would provide a diversity of perspectives across the 189 registered HRECs.

Survey items were developed following a review of peer-reviewed literature and ethical guidelines (see the study protocol for details¹²), and then reviewed and refined by the Aboriginal and Torres Strait Islander author team who have decades of experience, expertise and recognised leadership in Aboriginal and Torres Strait Islander health and medical research and working knowledge of the operation of HRECs. Survey items were pilot tested and amended according to feedback from Aboriginal and Torres Strait Islander researchers and community members. During piloting, individuals were asked to suggest any revisions needed to ensure that items were culturally appropriate, acceptable, and relevant and meaningful to the stated aims of the study ([Supporting Information, Box 1](#)). Data were collected online using the REDCap (Research Electronic Data Capture) platform and securely stored.¹³ The reporting of this study adhered to the CONSolidated critERia for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) statement ([Supporting Information](#)).

1 Participants' demographic characteristics

Characteristics	Participants
Survey participants	229
Age	
< 25 years	1 (0.4%)
25–34 years	12 (5.2%)
35–44 years	38 (17%)
45–54 years	48 (21%)
55–64 years	75 (33%)
65–74 years	37 (16%)
≥ 75 years	18 (7.9%)
Gender	
Woman or female	135 (59%)
Man or male	93 (41%)
Prefer not to say	1 (0.4%)
Aboriginal and Torres Strait Islander identity	
Aboriginal	10 (4.4%)
Torres Strait Islander	1 (0.4%)
Aboriginal and Torres Strait Islander	1 (0.4%)
Other Indigenous population	3 (1.3%)
Non-Indigenous	214 (93%)
Location of committee	
New South Wales	52 (23%)
Victoria	52 (23%)
Queensland	53 (23%)
Northern Territory	14 (6.1%)
Western Australia	24 (10%)
South Australia	12 (5.2%)
Tasmania	5 (2.2%)
Australian Capital Territory	14 (6.1%)
Prefer not to say	3 (1.3%)
Remuneration	
Non-financial (eg, part of academic service, work, volunteer, honorary position)	169 (74%)
Financial	58 (25%)
Missing	2 (0.9%)
Ethics committee type	
Institutional committee (eg, university, research institute)	129 (56%)
Health service committee (eg, local health district, hospital, health centre)	87 (38%)
Aboriginal-specific committee	5 (2.2%)
Aboriginal-specific subcommittee	0
National or government committee	5 (2.2%)
Prefer not to say	3 (1.3%)

1 Continued

Characteristics	Participants
Interview participants	13
Age	
25–34 years	2
35–44 years	1
45–54 years	2
55–64 years	6
65–74 years	1
≥75 years	1
Gender	
Woman or female	7
Man or male	6
Aboriginal and Torres Strait Islander identity	
Aboriginal	2
Non-Indigenous	11
Current human research ethics committee member	
Yes	12
No, but was a member within the previous 5 years	1
Location of committee	
New South Wales	2
Victoria	3
Queensland	2
Northern Territory	3
Western Australia	2
Australian Capital Territory	1
Ethics committee type	
Institutional committee (eg, university, research institute)	8
Health service committee (eg, local health district, hospital, health centre)	3
Other	2

Interview methods

Interviews were conducted via videoconference and audio recorded. Interviews were guided by three domains of enquiry: HREC structures; challenges with current ethics review and approval processes; and what is needed to improve ethical governance. Interviews took about 30–60 minutes. Non-Indigenous participants were interviewed by two non-Indigenous research fellows (KB or RM). Indigenous participants were interviewed by an Aboriginal researcher (FC, a PhD candidate).

Data analysis

Survey and interview demographics were summarised as counts and percentages using SPSS Statistics v23 (IBM). Interviews were analysed thematically using template analysis¹⁴ in NVivo 13 (Lumivero) by two independent researchers with qualitative

research experience (KB, RM). KB and RM familiarised themselves with the data through conducting interviews, reading transcripts, and reviewing audio recordings. They then independently coded the first two interviews, before meeting to discuss. An initial template was created to help guide the coding process, define codes, and work over developing themes before applying them to the entire data set. This template was adapted, changed and reworked as needed. In total, four of 13 interviews were dual coded, four were independently coded by KB, and five were independently coded by RM before themes were drafted. Key themes were developed through collaborative yarning with MK and organised alongside the relevant research aim. Results are reported in line with the Consolidated Criteria for Reporting Qualitative Research checklist¹⁵ and the Consensus Based Checklist for Reporting of Survey Studies.¹⁶

Ethics approval

This research was developed and implemented following national consultation and collaboration with Aboriginal and Torres Strait Islander researchers, Aboriginal community-controlled health organisation representatives and peak bodies, Aboriginal community members, and the National Health Leadership Forum (now known as the National Indigenous Health Leadership Alliance). The research was conducted in line with key ethical guidelines and principles.^{7,17,18} In lieu of an Aboriginal and Torres Strait Islander-led and nationally endorsed process for ethics approval of national Aboriginal and Torres Strait Islander health and medical research, ethics approval for this phase of the research was obtained from the Aboriginal Health and Medical Research Council of NSW Human Research Ethics Committee (1924/22), Australian Institute of Aboriginal and Torres Strait Islander Studies Research Ethics Committee (EO323-20220414) and University of Newcastle Human Research Ethics Committee (H-2022-0211) to uphold ethical governance, safety and benefit of the research as determined by Aboriginal and Torres Strait Islander people at a state and national level. All participants provided informed consent for participation.

Results

The survey was commenced by 276 individuals. Some participants were excluded as they did not meet the eligibility criterion of being a current or past (previous 5 years) member of an ethics committee (34 people), indicated that their ethics committee did not receive applications related to Aboriginal and Torres Strait Islander research (6 people), were detected as duplicate completions (4 people), or did not answer all questions relating to this article (3 people). A total of 229 HREC members were included in the analysis and 13 HREC members participated in an interview. Participant demographics are presented in [Box 1](#), full survey results are presented in [Box 2](#), and illustrative quotes from interviews can be found in [Supporting Information](#), table 1.

HREC membership structure

One hundred and fifteen of 221 survey participants (52%) reported that their HREC had an Aboriginal and/or Torres Strait Islander representative position. Of those who reported that their HREC had a representative position, 99 respondents (86%) reported that the position was filled.

Participants reported the position to be considered highly valued to upskill non-Indigenous committee members and “exposes more academics to issues of Indigenous research”

2 HREC structures, processes and operation for review of Aboriginal and Torres Strait Islander health research for 229 participants

Characteristic	Participants
Reported HREC membership structure	
Aboriginal and/or Torres Strait Islander representative position*	
Yes	115 (52%)
No	64 (29%)
Don't know	42 (19%)
Aboriginal and/or Torres Strait Islander representative position filled†	
Yes	99 (86%)
No	9 (7.8%)
Don't know	7 (6.1%)
Review, approval and monitoring processes	
Committee ratification of Aboriginal-specific ethics approvals*	
Yes	151 (68%)
No	24 (11%)
Don't know	46 (21%)
Aboriginal-specific approval for general population studies required	
Never	15 (6.6%)
Sometimes	68 (30%)
Often	43 (19%)
Always	73 (32%)
Don't know	30 (13%)
Ethics committee provides training for members about Aboriginal and Torres Strait Islander health research	
Yes	90 (39%)
No	139 (61%)
Ethics committee provides training for researchers about Aboriginal and Torres Strait Islander health research	
Yes	67 (29%)
No	162 (71%)
Ethics committee recommends training for researchers about Aboriginal and Torres Strait Islander health research‡	
Yes	85 (37%)
No	143 (63%)
Missing	1
Operations	
Number of Aboriginal and Torres Strait Islander-specific applications received annually to committee‡	
10 or less	101 (50%)
11 or more	102 (50%)
Missing	26

Continues

2 Continued

Characteristic	Participants
Manageability of the quantity of ethics applications for Aboriginal and Torres Strait Islander-specific research‡	
Completely manageable	89 (45%)
Mostly manageable	60 (30%)
Fairly manageable	38 (19%)
Somewhat manageable	12 (6%)
Not at all manageable	1 (0.5%)
Missing	29
Perceptions of level of quality of Aboriginal-specific applications‡	
Very good	14 (7.3%)
Good	89 (46%)
Fair	78 (41%)
Poor	9 (4.7%)
Very poor	2 (1.0%)
Missing	37
Common initial outcome of ethics applications‡	
Approved with no amendments	5 (2.6%)
Approved with minor amendments	147 (77%)
Major amendments required	38 (20%)
Rejected	1 (0.5%)
Missing	38
Number of reviews that an average application receives from their committee‡	
0–1	75 (39%)
2	69 (36%)
3 or more	49 (25%)
Missing	36
Key areas that applicants need to address with additional assistance or amendments before receiving ethics approval§	
Appropriate consultation with Aboriginal and Torres Strait Islander community	131 (57%)
Appropriate partnerships with Aboriginal and Torres Strait Islander community	109 (48%)
Appropriate consent processes	88 (38%)
Appropriate Aboriginal and Torres Strait Islander governance of the research	79 (34%)
Culturally sensitive practices	78 (34%)
Research design	76 (33%)
Appropriate recruitment processes	76 (33%)
Having appropriate information statements on consent forms	72 (31%)
Addressing Aboriginal and Torres Strait Islander ethical values/principles in application	72 (31%)
Appropriate cultural advisory	62 (27%)

Continues

2 Continued

Characteristic	Participants
Benefit of the research for Aboriginal and Torres Strait Islander community	60 (26%)
Appropriate research team members	54 (24%)
Dissemination of findings to community	53 (23%)
Potential identifying information	40 (17%)
Risks and burdens associated with research not addressed/mitigated	36 (16%)
Dissemination of findings to participants	34 (15%)
Data storage and access	29 (13%)
Risks and burdens associated with research are too high	17 (7.4%)
Other	16 (7.0%)
Planned activities for the data	15 (6.6%)
Having appropriate funding	9 (3.9%)

HREC = human research ethics committee. * Denominator for percentages is 221 as respondents from Aboriginal-specific HRECs and Aboriginal-specific subcommittees were not asked these questions. † Denominator for percentages is 115 as only respondents who indicated that their HREC had an Aboriginal and/or Torres Strait Islander representative position answered this question. ‡ Denominator for percentages is less than 229 as missing data were excluded. § Percentages do not sum to 100% as participants could select more than one response. ◆

(P8). Participants indicating absence of an Aboriginal and/or Torres Strait Islander representative highlighted the value they believed it would add to their ethics review process:

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 [Aboriginal Health and Medical Research Council] is culturally safe. I think that there would be great value in that. (P4)

One interview participant reported that the Aboriginal and/or Torres Strait Islander representative position was held by a non-Indigenous person.

It was common for interview participants who did have a specific representative position to indicate trouble filling it. Participants also suggested perceptions of high workloads and additional burden of review being placed on few Aboriginal and Torres Strait Islander people, disenfranchisement with academia and research, and limited remuneration opportunities for the role. One participant stated: "Indigenous academics, if anything, have just got more weight of expectations on them than everyone else" (P5).

Some participants reported relying on external consultation processes:

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 [re]viewer for any Indigenous project. (P8)

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. (P3)

Review and monitoring processes

One hundred and fifteen of 221 survey participants (68%) reported that their HREC ratified AHREC approvals. One interview participant recognised the impact that this may have on AHRECs and other localised communities as a growing number of AHRECs require pre-approval and engagement for applications:

So, those burden issues have to be dealt with by community and not by me ... So, how much training, exposure, expertise will the AIATSIS [Australian Institute of Aboriginal and Torres Strait Islander Studies] members have to be able to pick up the load that's coming their way? (P4)

Whether AHREC approval was required for general population studies varied between survey participants (never, 15 respondents [6.6%]; sometimes, 68 [30%]; often, 43 [19%]; always, 73 [32%]; don't know, 30 [13%]). Interviews revealed uncertainty about when general population research should include AHREC approvals. It was reported by some interview participants that the chair is responsible for deciding whether research should be deemed as Aboriginal research:

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)

Interview participants raised concerns about lack of oversight of the application process, monitoring of research after approval, or how to manage complaints. One interview participant raised issues with the application process being ungoverned:

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)

Another participant highlighted that there was no structure to monitor and evaluate ethical practice and partnerships described in the application throughout the duration of the project:

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)

Review and approval operations

Survey responses to the number of Aboriginal and Torres Strait Islander-specific applications received annually was

split between ≥ 11 (102 [50%]) and ≤ 10 (101 [50%]). Noting that most survey respondents were not Aboriginal or Torres Strait Islander, our findings revealed that the number of applications to be reviewed was reported as manageable by most survey participants (149 of 200 [75%]). However, two Aboriginal interview participants noted issues of cultural burden, having a higher load of applications, and often reviewing a large number of applications at one meeting (P12, P13).

There were mixed perceptions about the quality of applications across both interviews and survey responses. Nearly half of all survey participants reported receiving fair, poor or very poor quality applications (89 of 192 [46%]). The most common initial outcome of applications was reported by survey participants as approved with minor amendments (147 of 191 [77%]) and receiving 0–1 revisions (75 of 193 [39%]).

Some interview participants who praised the standard of applications attributed quality to the pre-approval requirements from AHRECs before it reached their HREC for ratification. Other interview participants stated that low quality applications would be filtered out by the secretary and would not go to review without alteration:

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).

Interview participants indicated that high quality applications were easier to manage and would typically “fly through” (P6) review. Some interview participants emphasised that high quality applications were usually from Indigenous researchers and demonstrated engagement and consultation:

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. (P8)

One Aboriginal interview participant commented on the need for appropriate community engagement in research development: “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). This is consistent with responses from survey participants, who selected lack of consultation (131 of 229 [57%]) and lack of partnerships (109 of 229 [48%]) as the key areas where applicants require amendments before approval is granted (Box 2).

Discussion

To our knowledge, this is the first national Australian study to quantitatively and qualitatively explore the perspectives of HREC committee members involved in reviewing and monitoring Aboriginal and Torres Strait Islander health and medical research. In examining HREC structures, processes and operations, we identified key areas of recommended change to improve ethical governance. Participants in our study recognised the importance of Aboriginal and Torres Strait Islander oversight in ethics processes, but also identified barriers within current systems.

As previously reported, limited health and medical research conducted has been reviewed and monitored by Aboriginal

and Torres Strait Islander people.¹ We found that just over half of respondents reported having an Aboriginal and Torres Strait Islander representative position, even less had the position filled and about one-fifth were not sure if there was a position. The national statement requires HREC assessment 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”.¹⁹ Furthermore, the statement explicitly states: “These ethical guidelines are not simply a set of rules. Their application should not be mechanical. It always requires, from each individual, deliberation on the values and principles, exercise of judgement, and an appreciation of context”.¹⁹ The lack of Aboriginal and Torres Strait Islander representative positions directly influences the deliberative decisions made on the quality and safety of research proposals.²⁰ Furthermore, we argue that one person on a committee cannot represent a whole population group. It is therefore imperative that the lack of representation is urgently addressed to ensure that Aboriginal and Torres Strait Islander expert review is included in all HREC processes. To do this, barriers in appointing and supporting representative positions must be acknowledged, including the high burden and workload. Support should consider remuneration for the specialist expertise and knowledges of Aboriginal and Torres Strait Islander people.

Our findings suggest that only a small proportion of committee members have received training from their HREC specifically for Aboriginal and Torres Strait Islander health research. This is particularly concerning given the lack of representative positions reported. Standardised training in Aboriginal and Torres Strait Islander health research and place-based cultural knowledge is critical to ensuring culturally competent and ethically sound research review; and should be developed, established and led by and for Aboriginal and Torres Strait Islander health researchers.

Our study found that AHRECs are highly valued and acknowledged as experts, but are likely to be carrying significant responsibility and burden for upholding ethical governance. While it is commendable that nearly three-quarters of participants reported that their committee ratifies AHREC approvals, acknowledging that Aboriginal and Torres Strait Islander health research outputs have increased threefold since the establishment of Closing the Gap,²¹ we must consider the additional burden on the three AHRECs. We join calls for the establishment of AHRECs in all states and territories and a national committee to support ethical governance.²² This is particularly pertinent as our findings reveal that AHRECs currently absorb the onus of ensuring that ethical research guidelines are appropriately applied to Aboriginal and Torres Strait Islander health research, with committee members commenting on the high quality of applications submitted after AHREC approval.

Lengthy ethics approval processes are well documented as a barrier to Aboriginal and Torres Strait Islander health research.²³ However, our findings show that higher quality applications reduce the time to process and approve applications. Although Aboriginal and Torres Strait Islander consultation, engagement and partnerships are embedded through all ethical guidelines and principles for Aboriginal and Torres Strait Islander health research,^{5,6,24} these areas were the most common issues raised during ethical review by participants. The high quantity and low quality of applications received which require re-review processes is likely to be associated with the reported lengthy timeframes.

Our findings reinforce decades-long recommendations for the establishment of structures that acknowledge Aboriginal and Torres Strait Islander expertise in ethics and the need for standardised monitoring and reporting processes for all Aboriginal and Torres Strait Islander health research.^{2,25} A clear example of the need for cohesive guidelines and standardised processes is emphasised by our results, which show that requirements are not always clear and judgement is often deferred to an HREC chair rather than a representative body. Furthermore, we found that there is not always a clear pathway for complaints processes, nor transparency on complaint outcomes. A recent NHMRC HREC report noted that there were 13 registered complaints about researchers or the conduct of approved research that involved Aboriginal and Torres Strait Islander people.¹ There are no available details on how complaints are managed beyond the NHMRC and Universities Australia guide,²⁶ which places the authority in the institution affiliated with the research. Complaints received by HRECs and how these are investigated and dealt with should be part of annual HREC activity reporting.

The NHMRC guidelines acknowledge the rights of Aboriginal and Torres Strait Islander people to be involved in all aspects of research undertaken and acknowledge the principles outlined in the United Nations Declaration on the Rights of Indigenous Peoples, notably the right to self-determination.⁵ In reviewing HREC structures, processes and operations related to Aboriginal and Torres Strait Islander health research, we found that the current landscape of ethical governance, approval and monitoring has significant areas for improvement. It is therefore imperative that cohesive guidelines and streamlined processes are established and implemented to uphold agreed rights.

Limitations

This was not a representative study of all HRECs and our findings should be interpreted accordingly. This study engaged HRECs members rather than a single committee representative in order to obtain the varied experiences and expertise of the member base. Consequently, multiple participants might have participated in the survey for the same committee, which may have skewed the data. As we approached NHMRC-registered HRECs and asked them to forward the link to our survey to individual committee members, we are unable to determine a response rate for the survey. While survey items were informed by a review of peer-reviewed literature and ethical guidelines

and by community feedback and pilot testing, we do not have quantitative data to validate the efficacy and reliability of items. We also acknowledge that ethical processes vary across individual states and territories and HRECs.

Conclusions

HRECs are responsible for reviewing, approving and monitoring research practice and have a pivotal role in ensuring that research conducted with Aboriginal and Torres Strait Islander people is safe. We found that Aboriginal and Torres Strait Islander people and AHRECs carry an important role and consequent burden in the review and approval of health research involving Aboriginal and Torres Strait Islander people. We identified that Aboriginal and Torres Strait Islander people are not presently involved in all aspects of research, including the governance, approval and monitoring of practice, within current HREC structures. To address these issues of the current system, we call for cohesive and standardised processes and guidelines which uphold Aboriginal and Torres Strait Islander rights and expert knowledges in ethical processes and operations used for reviewing and approving Aboriginal and Torres Strait Islander health and medical research.

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Data sharing: In line with Indigenous data sovereignty and Aboriginal and Torres Strait Islander ethical research principles, no data sharing is available from this study. ■

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Supporting Information

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