

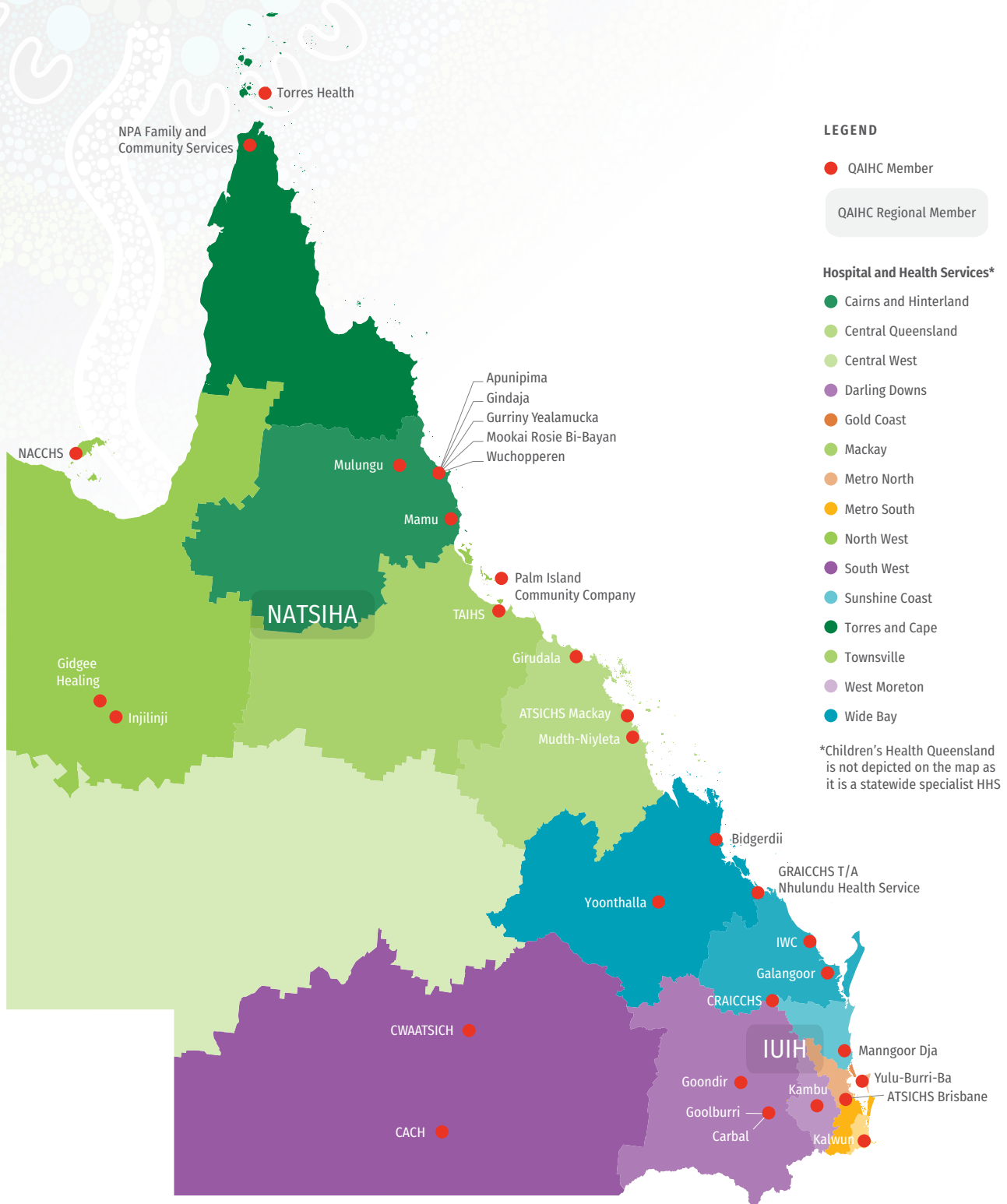


Research Our Way: Closing the Gap in
Aboriginal and Torres Strait Islander Human
Research Ethics Governance in Queensland

Acknowledgement

We acknowledge and wholly support all Traditional Owners for their continuing connection to this country and their communities. We recognise their continuing connection to these lands and waters and thank them for protecting this country and its ecosystems since time immemorial. We pay respect to them and to their Elders past, present and emerging.

Our Members





The Queensland Aboriginal and Islander Health Council (QAIHC) is a leadership and policy organisation.

We were established in 1990 and are the peak organisation representing all Aboriginal and Torres Strait Islander community controlled health organisations (ACCHOs) in Queensland at both a state and national level.

The QAIHC Membership is comprised of ACCHOs located throughout Queensland. Nationally, we represent Queensland through its affiliation and Membership on the board of the National Aboriginal Community Controlled Health Organisation (NACCHO).



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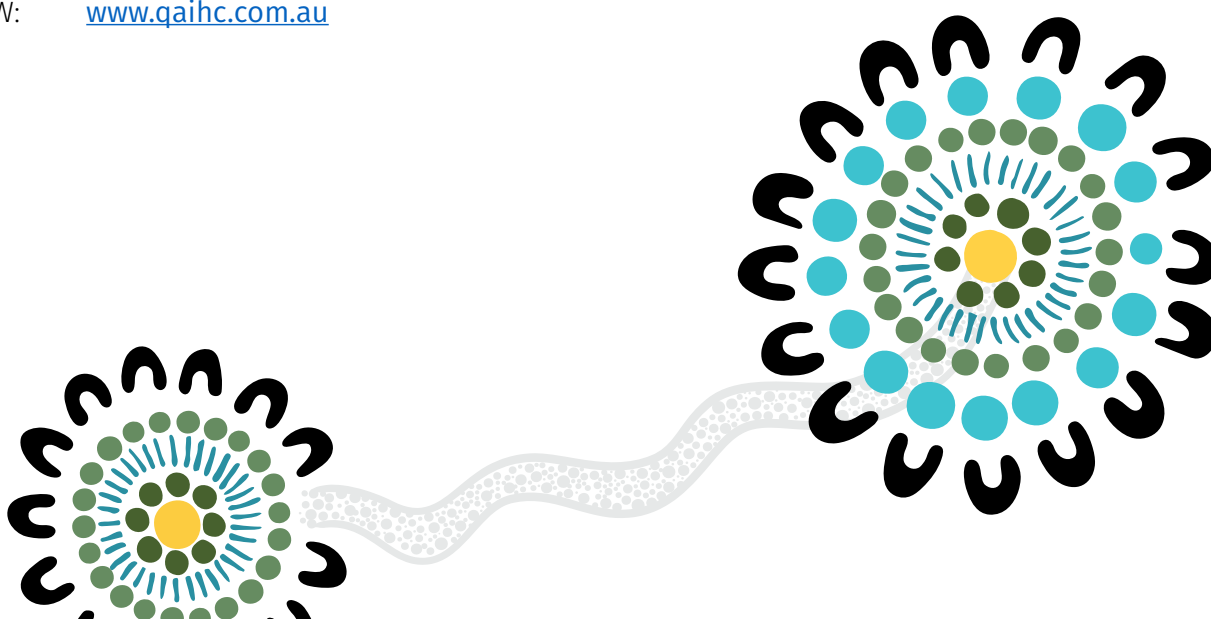
We acknowledge the people, organisations and communities who have contributed to development of this document; and the Lowitja Institute for its significant investments in Aboriginal and Torres Strait Islander research, and for funding and support for this project.

Terminology

Throughout this document, the terms “Indigenous”, “First Nations”, and “Aboriginal and/or Torres Strait Islander” peoples are used interchangeably. We acknowledge that use of these terms is a consequence of an aim to support readability and recognise their limitations in paying respect to the multitude of diverse, and unique First Nations of Australia. We acknowledge the rich traditional, cultural, social, and spiritual diversity of the First Peoples of Australia and their sovereign rights and responsibility as custodians and caretakers of their land, air and waters.

Approving Human Research Ethics Committee

This project was approved by Darling Downs Hospital and Health Service (HHS) Human Research Ethics Committee; ethics clearance reference HREC/2024/QTDD/107499.



Executive Summary

The Aboriginal and Torres Strait Islander community controlled health organisation (ACCHO) sector remains committed to listening, learning and implementing evidence-based practice into our ways of doing; informed by our knowing and being.

Continuous quality improvement (CQI) is an integral part of the sector, ensuring that we respond to community-identified health needs and priorities; developing solutions that are indicated and sensitive to our preferences; and that support a real-world benefit for the individuals, families and the communities we serve.

Research is an integral part of the CQI cycle and there is a continuing and significant investment across Australia in research for a health benefit, particularly funded by the National Health and Medical Research Council (NHMRC) and the Medical Research Future Fund (MRFF). It is essential that Aboriginal and Torres Strait Islander interests are managed by Aboriginal and Torres Strait Islander people and their representative entities. Research for us, by us, in alignment with our interests and priorities.

The research was led by three recognised Indigenous researchers working together to support this community-driven research project. Significant engagement and consultation with the ACCHO sector served as the basis for the work, complimented by deliberate engagements with Queensland Human Research Ethics Committees. Recommendations arising from the project serve as a basis for systems reform and evidencing self-determination through research.

Research findings make a significant contribution to understanding the need for research ethics governance by Aboriginal and Torres Strait Islander people and organisations. It describes an interest in, appetite for, and the feasibility of, an Aboriginal and Torres Strait Islander-led research ethics governance system in Queensland.

Recognising the impact, significance and influence of health research on policy and healthcare, 'Research Our Way: Closing the gap in Aboriginal and Torres Strait Islander Human Research Ethics Governance in Queensland' is an initiative of the Queensland Aboriginal and Islander Health Council (QAIHC). This project was funded by the Lowitja Institute.

Key Learnings

Through a series of conversations, surveys, yarning circles, and focus groups with people and organisations involved with research and research ethics governance across Queensland, the following was noted:

1. Research is central to continuous quality improvement (CQI) and an integral part of the core business of the Aboriginal and Torres Strait Islander community controlled health organisation (ACCHO) sector;
2. There is a genuine interest and identified need to support the establishment of an independent Queensland Aboriginal and Torres Strait Islander Human Research Ethics Committee (QATSIHREC);
3. There is a preference that the suggested research ethics governance entity (i.e. QATSIHREC) be housed in the ACCHO sector and serve a statewide remit.

Recommendations

In alignment with the research learnings, the following actions are recommended:

1. Resourcing to support the establishment of QATSIHREC;
2. Development of a research strategy to support ACCHOs to respond to and lead research on behalf of the sector.

Purpose and Scope

Alignment of research with the expectations and values of society is an essential part of ensuring the benefits of research outweigh risk to participants, the public and its priority populations.

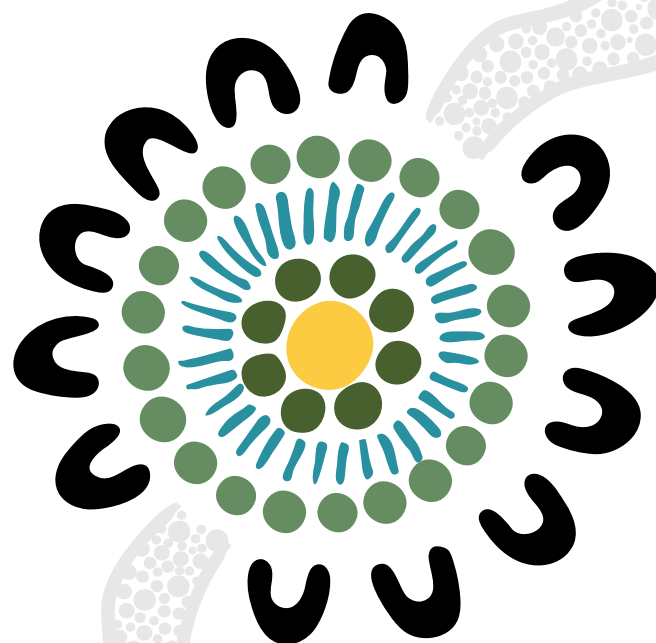
Research should involve the right people, asking the right questions, in the right way, for the right reasons^{1,2}. Beneficence and non-maleficence are fundamental principles governing the assessment of research activities and ensuring that societal benefits outweigh risk for participants, the public, researchers, organisations and the scientific community³⁻⁶.

This project served to explore the strengths and weaknesses of existing research ethics governance in Queensland. It focused on the adequacy of existing structures to receive, review and respond to proposals for research involving Aboriginal and Torres Strait Islander people⁷⁻⁹. The project engaged participants from ACCHOs across Queensland, alongside members of existing Human Research Ethics Committees (HRECs).

The project aimed to:

1. Describe the capabilities, capacity, limitations and strengths of existing research ethics governance systems.
2. Identify strategies that support research to align with the priorities, preferences and aspirations of Aboriginal and Torres Strait Islander people, communities and their champions.

At the time this project was undertaken, National Health and Medical Research Council (NHMRC) guidelines required HRECs to have an Aboriginal and/or Torres Strait Islander Elder or religious minister represented through membership of the committee to provide cultural/religious oversight [10-13]. For a range of reasons, many committees still lack Indigenous representation^{6, 8, 14}. This research explores interest in, and the benefits of, Aboriginal and Torres Strait Islander-led research ethics governance in Queensland; to describe benefit for Aboriginal and Torres Strait Islander peoples; Indigenous and non-Indigenous researchers; and research administrators.



Background

In Australia, Indigenous Research Ethics Committees (IRECs) play a vital role in ensuring that research involving Aboriginal and Torres Strait Islander peoples is conducted in accordance with protocols, values and preferences of First Nations Australians. They are an essential part of ensuring Aboriginal and Torres Strait Islander peoples' right to self determination and to equitable access to health. It is widely recognised that there is a need for an increased investment in IRECs.

In Australia, there are five designated IRECs. These are:

1. Australian Institute of Aboriginal and Torres Strait Islander Studies Research Ethics Committee (AIATSIS REC).

Established under the Australian Institute of Aboriginal and Torres Strait Islander Studies Act (1989), the AIATSIS REC is the only national IREC. It reviews research from a range of stakeholders (including government, academia, and industry) responsible for research involving and claiming to benefit Aboriginal and Torres Strait Islander peoples. The AIATSIS Act (1989) mandates that AIATSIS provide leadership in ethics and protocols for research related to Aboriginal and Torres Strait Islander peoples¹.

2. The Aboriginal Health Research Ethics Committee (AHREC) of the Aboriginal Health Council of South Australia (AHCSA) was established in 1986¹⁵. It is a specialist committee that distinguishes between evaluations for research and commissioned purposes.

3. Aboriginal Health & Medical Research Council of New South Wales (AH&MRC) Ethics Committee.

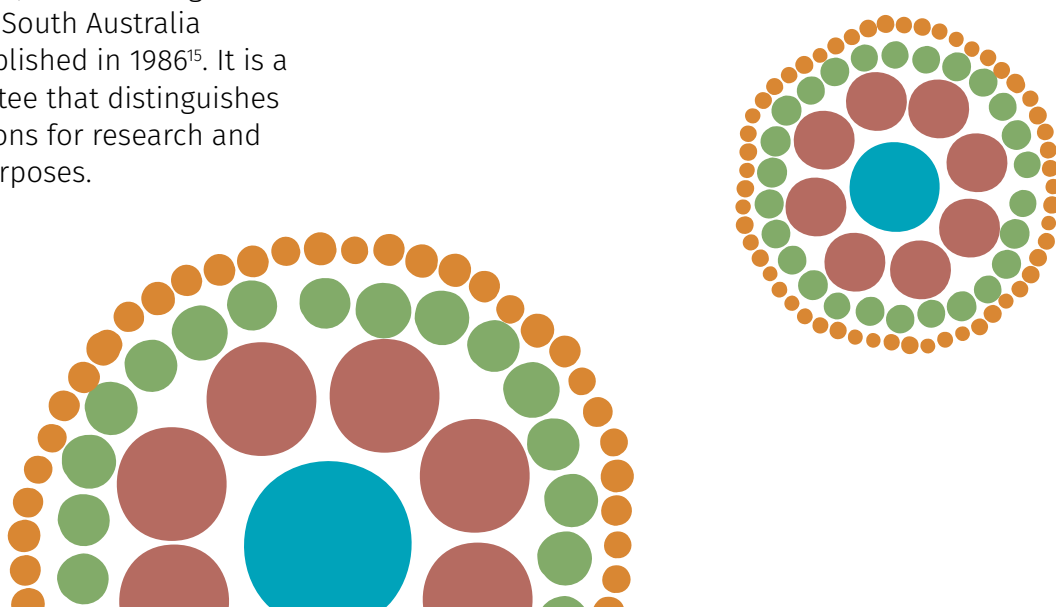
In 1996, the AH&MRC established the AH&MRC Ethics Committee to ensure that ethical research principles and outcomes align with the preferences and needs of Aboriginal people and their communities¹¹.

4. Western Australian Aboriginal Health Ethics Committee (WAAHEC).

The Western Australian Aboriginal Health Ethics Committee (WAAHEC) was established almost 30 years ago to support quality research that aligns with the needs of Aboriginal communities in Western Australia. Like every other IREC, the need for this committee arose from concerns about the quality, integrity and ethical conduct of research^{15, 16}.

5. Victorian Aboriginal Community Controlled Health Organisation Human Research Ethics Committee (VACCHO HREC).

Since 2018, VACCHO has been working to establish its own state-based HREC. Following calls to the Victorian Government, a research accord was developed and funding provided to develop a plan to establish a HREC. The newly established IREC reviews health and wellbeing research from a Victorian Aboriginal and Torres Strait Islander community perspective¹⁷.



In 2014, Griffith University's Indigenous Research Unit (working in collaboration with QAIHC, Queensland Health, and AIATSIS), facilitated a Lowitja Institute-funded roundtable to discuss Aboriginal and Torres Strait Islander health research ethics in Queensland. The roundtable recognised the significance of an NHMRC-commissioned review that noted inconsistencies in the application of principles relating to research involving Aboriginal and Torres Strait Islander people by Queensland HRECs.

The roundtable recommended a variety of actions to support ethical review of health research involving Aboriginal and Torres Strait Islander people of Queensland, including the establishment of a working party under QAIHC leadership and operating in collaboration with various stakeholders^{9, 14, 15}. The proposed working party was charged with:

- Establishing an IREC for Queensland;
- Developing and enacting a constitution and strategic plan; and
- Disseminating knowledge among stakeholders.

The working party was never established and none of the actions were commenced.

To date, Queensland is one of the only states in Australia without an IREC.

Lowitja Institute Grant

In November 2022, Ms Renee Williams, General Manager for Policy and Research, applied for a major grant from the Lowitja Institute supported by Associate Professor Greg Pratt (Central Queensland University) and Professor Ray Mahoney (CSIRO). The application included a letter of support from the Queensland Aboriginal and Torres Strait Islander Health Research Network (QATSIHRN), a group of Aboriginal and Torres Strait Islander researchers from across Queensland with expertise in health policy, research, and health service delivery from both a public and ACCHO perspective. The application was also endorsed by the QAIHC Board.

On peer review of the application by the Lowitja Institute, QAIHC was awarded \$200,000 for a 2-year project. Shortly after the grant was awarded, Ms Williams moved on from QAIHC and Associate Professor Pratt took on the role as principal investigator (working 1 day per week as a QAIHC employee for the duration of the project). Ms Williams and Prof Mahoney continued to serve as named Chief Investigators (CIs) on the project for its duration, their leadership as Aboriginal and Torres Strait Islander researchers and community champions serving as testament to the capability, quality, integrity and commitment of Indigenous-led research and ethics governance.

Acceptance of a conditional offer was provided to the Lowitja Institute on 1 February 2023, with the project formally commencing on 1 March 2023.

Over the life of the project, a number of variations were requested (and granted), including requests to extend the end date for the project due to the COVID-19 pandemic and its impact on the health service sector, causing delays in commencement of research activities.

Reports were periodically provided to the funding body describing progress in alignment with agreed milestones and key deliverables. Each report was submitted by Chief Investigator A (CIA – Associate Professor Pratt) acting as principal investigator and responsible party from an ethics approval perspective, with endorsement of the CI team. Each report was approved by the CEO of QAIHC. Submitted reports were accepted by the Lowitja Institute and aligned with a payment schedule for the project.

The fourth and final report was submitted on 8 March 2026 and included information similar to that required of the final HREC report. The final report was officially accepted by the Lowitja Institute on 24 March 2026 and the grant formally concluded.

Ethics Approval

Ethics approval was applied for via the Darling Downs Hospital and Health Service HREC. This HREC is both registered and certified with the NHMRC. The ethics application was lodged on 27 March 2023, with final approval being granted on 15 October 2024. Reasons for the delays are outlined in the “Barriers and Solutions” section of this report.

There were a number of amendments to the ethics clearance over the course of the project, relating to changes to project personnel, updating of participant information and consent forms, as well

as changes to the research protocol and timelines. All amendments were approved. The most significant change to the protocol for the project related to the recruitment strategy for participants and methods employed in yarning circle sessions. Specifically, in light of COVID-19, a move away from face to face focus groups toward online focus groups, complimented by one face to face meeting of ACCHOs.

Progress reports were submitted to the reviewing committee annually, describing progress, outputs, benefits and impacts in alignment with the aims of the study.

Methods

Underpinned by Indigenist research methods and reflecting a commitment to community driven research, self-determination and sovereignty, this study used a mixed-methods cross-sectional design. The design employed participatory action research and reflexive thematic methods to analyse qualitative data, which was collected through online surveys as well as online and face-to-face yarning circles with ACCHO staff and HREC personnel.

Participants

Eligible participants were:

- a)** Staff of ACCHOs who had been nominated by the CEO of their organisation based on an interest or experience of being involved in receiving, reviewing or responding to research involving Aboriginal and/or Torres Strait Islander people.
- b)** Members of Queensland HRECs with an interest or experience in being involved in receiving, reviewing or responding to research involving Aboriginal and/or Torres Strait Islander people.

To avoid any potential, perceived and/or real conflict of interest, the reviewing HREC did not participate in the project. Participants from eligible HRECs represented a cross section of Hospital and Health Service (HHS)

and university-based HRECs from across Queensland.

Online Surveys

Eligible participants representing the two stakeholder groups (i.e. ACCHO staff and HREC members) were surveyed separately. Survey questions were structured to elicit responses relevant to each of the target groups and their experience of receiving, reviewing, and responding to requests to support research involving Aboriginal and/or Torres Strait Islander people.

In accordance with QAIHC communication policies, letters of invitation (n=33) were sent by the Executive Assistant acting on behalf of the QAIHC Chief Executive Officer. The letters invited nomination of ACCHO staff who consented to be contacted by a member of the research team. Subsequent communication between a member of the research team and nominated ACCHO staff invited participants to anonymously complete an online survey, which asked about their experience with research (Appendix 1). Surveys remained open for one month and two reminders were sent to maximise completion rates.

In addition to the recruitment process for ACCHO participants, invitation letters were sent to chairs and co-ordinators of all NHMRC-registered Queensland HRECs (n=67, as of February 2024).

Letters from a member of the research team invited recipients to participate in an anonymous online survey about their experience with Aboriginal and Torres Strait Islander research; processes for managing applications; and training in ethical research standards (Appendix 2). The survey was open for one month and two reminders were sent.

QAIHC Members Research Workshop

The QAIHC Members Research Workshop was a full day activity hosted at QAIHC in Brisbane, Australia on 28 April 2025 (Appendix 3). Invitations were sent to QAIHC Member executives, inviting services to nominate an attendee. A member of the research team invited nominated ACCHO personnel to attend the workshop. Travel and accommodation expenses for participant attendance were covered by the project budget. All participants completed a Participant Information and Consent Form (PICF) prior to the workshop.

Participants were allocated to one of three tables with between 5 and 7 participants per table. A member of the investigator team sat at each table and was responsible for an audio recording device placed on their table. Only the yarning circle sessions were recorded. The first part of the workshop served to inform participants about the project, its rationale, aims, and objectives.

This brief introduction was followed by an information session and panel discussion. The discussion involved three leading Indigenous researchers speaking to: research, research governance, ethics and ethics governance. This session and the subsequent panel discussion offered the audience an opportunity to ask questions about the topics, alongside hearing about the experiences of the panel. Questions put to the panel included queries about how research

addresses Indigenous health concerns, the importance of capacity and capability building, and differences between researcher-led, community-led and ACCHO-led research.

The two yarning circle sessions served as the main source of qualitative data for the workshop, focusing discussion in terms of:

1. Reflecting on the experiences of the ACCHO sector.
2. Reflecting on the preferences of the ACCHO sector.

The workshop and its yarning circle sessions were facilitated by the CIA Associate Professor Pratt, with each session covering one of four different but interrelated topics (Appendix 5). Each yarning circle session ran for approximately 15 minutes, at the end of which attendees were invited to complete a poll using interactive online polling software, Mentimeter. Interactive Mentimeter polling allowed participants to contribute to the yarning circle session anonymously and independently of group discussions.

Depending on the topic of discussion for the preceeding yarning circle session, participants were asked to rate, rank and/or confirm their agreement/disagreement with statements about research, research governance, ethics and ethics governance (Appendix 6). The two yarning circles generated approximately nine hours of audio recordings that were transcribed and analysed using reflexive thematic methods, which were confirmed through discussions and deliberation among the investigator team. In accordance with the project's ethics approval conditions, all recordings, transcriptions and data collected were stored securely on the QAIHC server and access limited to the QAIHC-based investigator team.

Preliminary results of the study were presented as part of an oral presentation at the Lowitja Conference in June 2025. No photography was permitted at the event. The thematic analysis and Mentimeter results are presented in the results section of this report.

HREC Online Yarning Circle Session

The investigator team invited the chair and co-ordinator of each eligible HREC to participate in an online yarning circle session. Two HREC focus group sessions were hosted via Microsoft Teams on 30 June and 10 July 2025, providing an opportunity for as many eligible participants to attend as possible. To ensure that no committee was overrepresented, a maximum of two representatives were invited to attend.

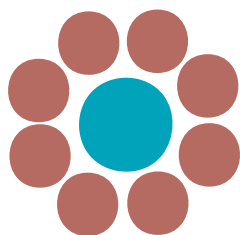
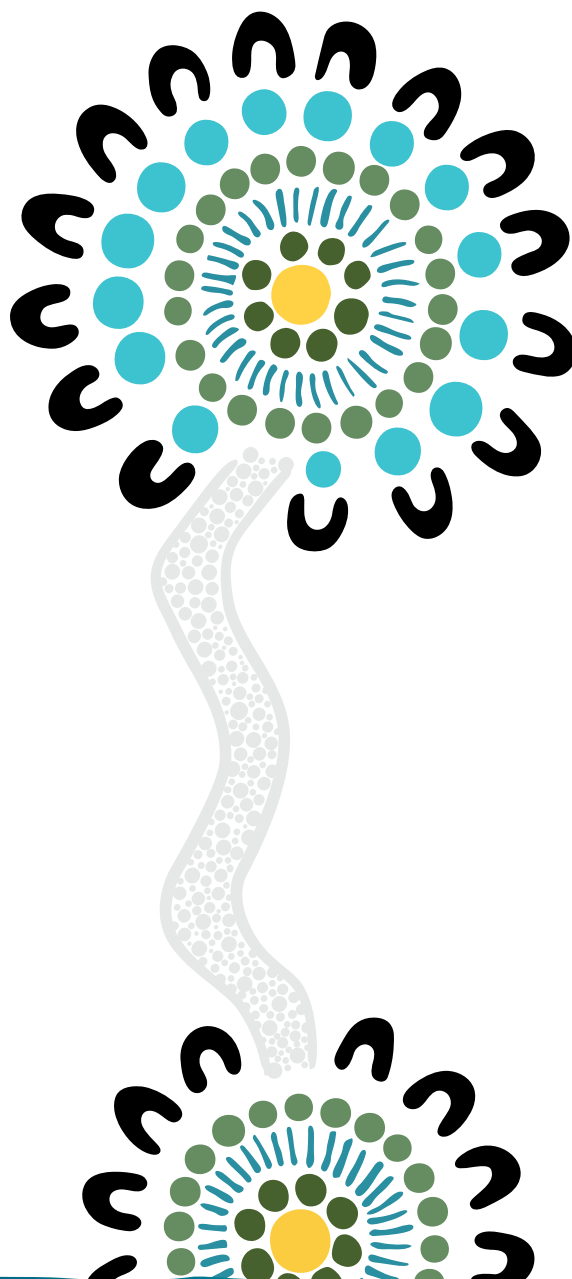
The yarning circle sessions served as an opportunity for HRECs to describe their experiences of reviewing applications for research involving Aboriginal and Torres Strait Islander peoples. Topics covered in the yarning circle sessions included:

1. Reflecting on the experiences of HRECs
2. Reflecting on the preferences of HRECs.

Participants could elect not to appear on camera. However, all agreed to be seen. At the end of each yarning circle session, participants were asked a series of questions and given the opportunity to provide individual responses anonymously through Mentimeter. Polling comprised open and closed questions across eight topics (Appendix 6). All participants completed a PICF prior to participating in the session.

Each session was approximately two hours in duration and was recorded using a handheld audio recording device positioned close to the speaker of the facilitator's (CIA Pratt) computer. To maintain a degree of anonymity for participants, sessions were not recorded using integrated Microsoft Teams functionality. A member of the investigator team uploaded the recording for each session to the ethics-approved secure QAIHC server.

Audio recording transcription enabled the thematic analysis. Reflexive thematic analysis (RTA) was used to analyse transcriptions, as well as discussion of Mentimeter responses and results among the investigator team to reach consensus about themes.



Results

Online Surveys – ACCHO Responses

Thirty-three QAIHC Member CEOs were invited to nominate a staff member to participate in the project. Nine participants representing six localities and approximately one third of the sector completed the online survey.

Table 1 describes the geographic locations represented by ACCHO respondents. All respondents indicated they received requests to be involved in research, with three indicating they do not have a process for managing these requests. Of the nine respondents, four identified they have

designated staff to manage requests to be involved in research, while six participants indicated their organisation is regularly involved in the co-design of research projects. One respondent indicated they do not actively promote and encourage involvement of Aboriginal and/or Torres Strait Islander peoples in research.

Consistent with other feedback received anecdotally from ACCHOs, all survey respondents indicated an interest in participating in a workshop to discuss their preferences and experiences of research.

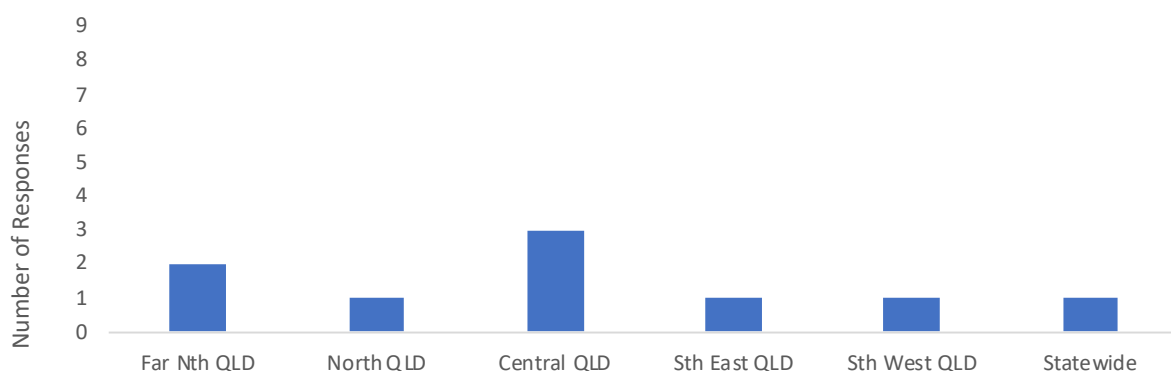


Table 1: ACCHO respondents by region

Table 2 describes the diversity of responses from ACCHO participants in relation to how they manage research requests and the ethics

processes they use to make a decision about research requests. Respondents were able to provide more than one response.

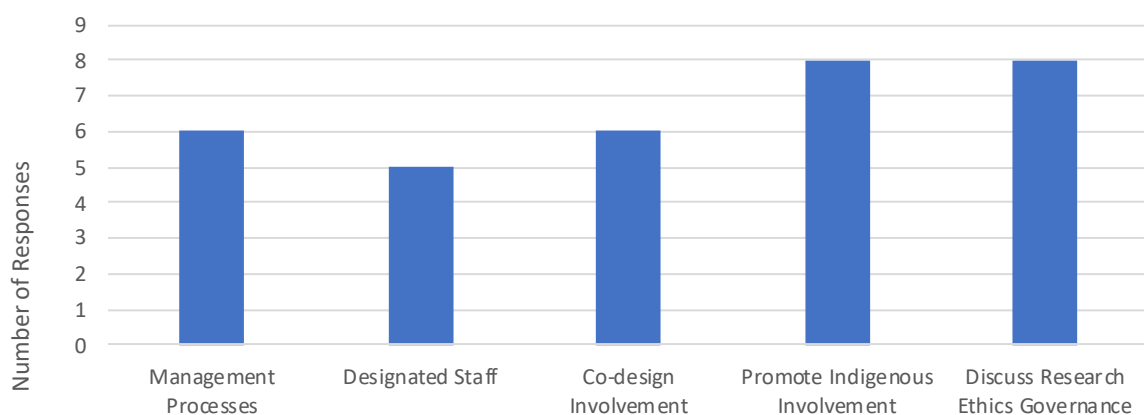


Table 2: ACCHO typical responses to research requests and resourcing

Online Surveys – HREC Responses

At the time of HREC survey commencement, 30 Queensland HRECs were registered with the NHMRC. By the time survey data collection was completed in November 2024, two committees had amalgamated, one advised they do not review human research, and the approving HREC for the project declined to participate due to conflict of interest concerns. Invitations were sent to chairs and co-ordinators for the 27 eligible HRECs (total number of invites n=67). Twenty-one responses were received from participants representing Queensland HRECs.

Table 3 describes the geographic locations from which HREC respondents identified they received applications seeking ethics approval for research involving Aboriginal and Torres Strait Islander people. One respondent indicated they do not receive applications for research involving Aboriginal and/or Torres Strait Islander people, while one advised they could not participate due to time constraints. However, they asked to be included in updates and advised of recommendations arising from the project, particularly the potential for establishment of a Queensland Aboriginal and Torres Strait Islander HREC.

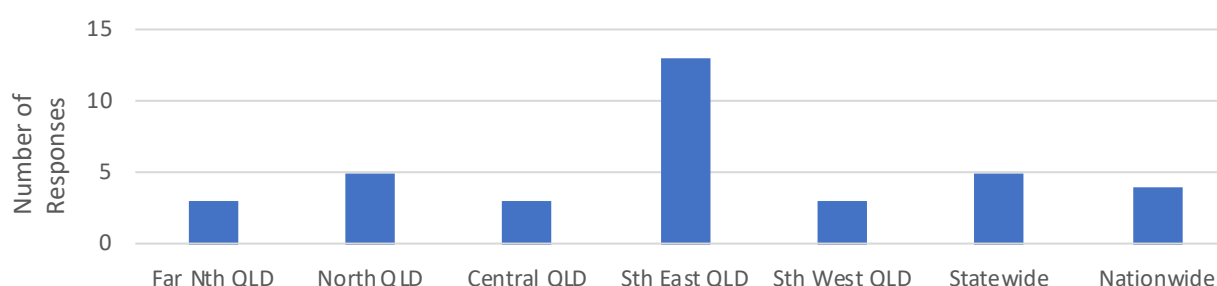


Table 3: HREC respondents by geographic locations of applications

Table 4 describes processes HRECs use for reviewing Indigenous research applications. Twenty respondents noted they actively promote and encourage researchers to be familiar and comply with NHMRC ethical guidelines for research involving Aboriginal and/or Torres Strait Islander people. Similarly, twenty respondents reported they actively promote and encourage researchers to comply with the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander research¹. Two respondents indicated they refer to AIATSIS REC, while one indicated their process varies depending on whether First Nations communities are involved in the study (and thus requires evidence of support from the community). Sixteen respondents noted they provide training opportunities for their

members applying ethical standards for research involving Aboriginal and/or Torres Strait Islander people.

Further to this, two respondents indicated they refer to interstate IRECs to supplement their ethics approval application capability, while two respondents indicated their current processes do not include a review by an Aboriginal and/or Torres Strait Islander person. Fifteen respondents identified they have Aboriginal and/or Torres Strait Islander representation on their committee and described their role as complimentary in supporting review of applications. Eight respondents described referring proposals to a person external to their committee, while three noted they refer to other governance groups, such as a community jury.

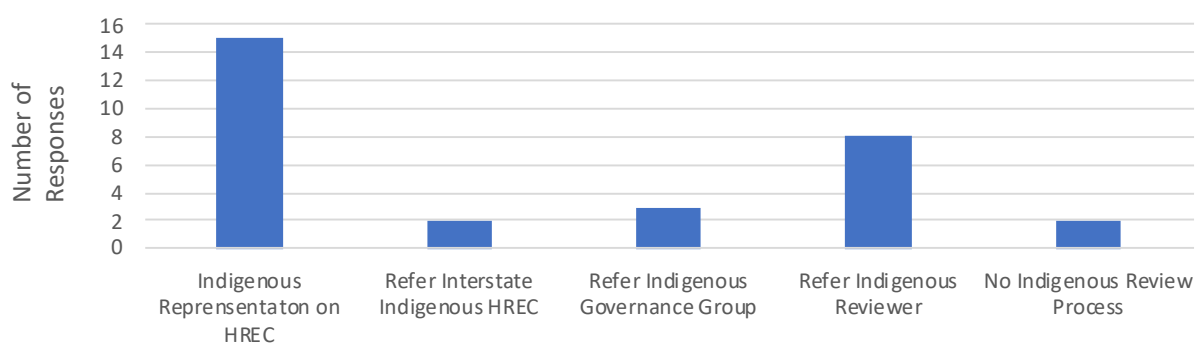


Table 4: HREC processes for reviewing Indigenous research applications

Ninety-five per cent of respondents indicated they wish to receive regular updates about a proposed project, while 67% indicated they would be interested in participating in a focus group.

The final question provided respondents with an opportunity to provide open ended statements. Four respondents provided feedback and acknowledged the

importance of the project. One respondent emphasised the need for all stakeholders to be involved via co-design processes. Another indicated that many of the principles applying to research involving Aboriginal and/or Torres Strait Islander peoples are applicable to other projects and participants; particularly concepts of community engagement and reciprocity.

Yarning Circle Sessions

Twenty-one people attended the QAIHC Members Research Workshop and participated in the yarning circles. Participants represented 11 ACCHOs, QAIHC, academia, and an IREC from another jurisdiction.

Twenty-two people attended either of the two online HREC yarning circle sessions. Participants represented academia (n=12) and Queensland Health HRECs (n=8), complimented by two members of the investigator team.

Yarning circle sessions facilitated at the QAIHC Members Research Workshop produced approximately 9 hours of audio recordings, while the HREC online yarning circle sessions produced approximately 4 hours of audio recordings.

Reflexive thematic analysis performed on transcripts of yarning circle sessions identified Community Driven Research and Sovereignty (CDRS) as the core theme supporting Aboriginal and Torres Strait Islander research ethics governance. CDRS contains six key domains, which align with and support the core theme (see Figure 1).



Figure 1: Key Domains of Community Driven Research and Sovereignty

Drivers supporting Community Driven Research and Sovereignty

“For effective research to happen it needs to align with community priorities and be culturally safe; research should not be done for research sake.”

(ACCHO Yarning Session Participant)

Community relationships are integral to CDRS, emphasising the importance of relationships built on trust and an ability to work together to co-design proposals that empower Indigenous people for a real-world impact. Significant elements acknowledged across the yarning circle sessions:

- The importance of relationships built on trust and researcher credibility
- The significance of two-way learning and co-leadership
- The need to manage research fatigue and gatekeeping.

“Work with community through communication, Indigenous reference groups, Elder groups, feedback loops, and engagement with community.”

(HREC Yarning Session Participant)

Research on community terms iterate the significance of community-driven research, specifically the role of community and its champions in developing, designing and conducting research in partnership with researchers to realise impact for community. Significant elements acknowledged in the course of yarning circle sessions:

- The need to respond to community-identified priorities
- The importance of research aligning with strategic priorities of ACCHOs
- The potential for data-driven decision-making by ACCHOs
- The implications of unsolicited proposals and their impact on ACCHO resources.

“Presenting the problem and proposing solutions without any engagement or bringing us on the journey is an automatic NO to a research proposal.”

(ACCHO Yarning Session Participant)

Governance describes structures that respect community, sovereignty and data ownership to drive quality research activities. Significant elements acknowledged in the course of yarning circle sessions:

- The importance of Indigenous data ownership and control
- The need to secure data and restrict access to approved persons for specific purposes
- Concerns about the secondary use of data
- Calls for Indigenous data governance frameworks.

“Some HRECs struggle to get Aboriginal and Torres Strait Islander members on their committees.”

(HREC Yarning Session Participant)

Capacity and capability activities support, nurture and recognise the expertise of an Indigenous research workforce leading and informing research that responds to community-identified priorities. Significant elements acknowledged in the course of yarning circle sessions:

- The need for dedicated research staff at ACCHOs
- The burden placed on ACCHOs from an in-kind support perspective
- Workforce shortages, particularly in rural/remote areas
- A need for funded and identified positions in research projects.

“Many research proposals do not include capacity building or funded positions for Indigenous staff.”

(ACCHO Yarning Session Participant)

Integrity and values are paramount to CDRS, supporting respectful research that aligns with the priorities, worldview, and the contributions of community member knowledge and skills. Significant elements acknowledged in the course of yarning circle sessions:

- The importance of cultural safety
- The need for Indigenous-led ethics governance
- The preference for informed consent processes (e.g., yarning-based)
- Resistance to extractive research practices.

"It comes back to governance over the project. Who owns the data and who is sharing the data."

(ACCHO Yarning Session Participant)

Infrastructure recognises the need to evolve systems to satisfy ethical requirements and inform real-world change. Significant elements acknowledged in the course of yarning circle sessions:

- Disconnect between research and health service delivery
- Desire for actionable research outcomes
- Recognition of the importance of community reference groups and advisory roles.

"There is a very big disconnect between community and researchers."

(HREC Yarning Session Participant)

Mentimeter Poll Results

Participants indicated they strongly agreed with the statements about Aboriginal and Torres Strait Islander research, specifically that it:

- a)** emphasises Aboriginal and Torres Strait Islander ways of being, knowing, doing
- b)** focuses on a concern of particular significance to Aboriginal and Torres Strait Islander people
- c)** is community driven
- d)** responds to a community-identified concern.

With respect to the statement that Queensland needs an Aboriginal and Torres Strait Islander Human Research Ethics Committee, the majority of participants representing both the ACCHO and HREC stakeholder groups supported the establishment of a QATSIHREC.

Asked if there are alternatives to a QATSIHREC, the majority of participants answered "No", with two people in favour of regionally based HRECs rather than a single statewide committee. The primary alternative suggested

by participants to a QATSIHREC, was an expert advisory panel, led by community, as part of the review process.

From a research governance perspective, it is clear there is often a conflict between the operating paradigms of CDRS and researchers.

Responses indicate that community relationships are not respected. ACCHOs are adamant that researchers were responsible for involving community in research, yet researchers expected ACCHOs to lead the way in informing and involving community.

Instead of growing ACCHO's capability and capacity, research is often extractive. Several ACCHO participants indicated an expectation they would provide "in-kind" support for research, yet few indicated funding extended to community-based researchers situated in ACCHOs.

Similarly, research is not requested on community terms. Researchers often expect in-kind support, yet few researchers offered their skills to help ACCHOs answer a community-identified need.

Finally, some research requests are not only on community terms, they also do not respect community governance, as few researchers list ACCHOs as a partner organisation in their grant applications.

Most participants indicated it was acceptable to say “No” to involvement in research, with the primary justifications being:

- a)** the research not being relevant or a community priority
- b)** no allocation of funding, resourcing or staffing to support community and ACCHO involvement
- c)** concerns about potential harm to participants.

From a community perspective, developing proposals that respond to community-identified health concerns was described by both ACCHO and HREC groups as paramount.

Recommendations for researchers about how to work with community included consultation, co-design, and empowerment. Participants emphasised these all require time and commitment and are “often overlooked by researchers.” One participant noted, “research, for research sake, is not the answer. Education on both sides, resourcing and capacity building are paramount.”

A recurring message was there needs to be engagement of all stakeholders, beneficiaries and partners across the lifecycle of each project, from proposal development to knowledge translation. Further, participants indicated research grant applications need to reflect engagement, including budgeting for local capacity building. The use of data with appropriate permissions for a public health benefit was recognised as a challenge for both Indigenous and non-Indigenous communities.

Barriers and Resolution

Various barriers were encountered over the life of the project and are discussed below. Significantly, the project manager position changed three times during the course of the project. Solutions took time to implement, adding to delays and adjustments to timelines, complicating planning and progression, with budget implications.

Ethics and Governance

Ethics approval was complicated by changes to project personnel, the need for a full human research ethics committee review, and questions from the approving committee regarding engagement of ACCHO members.

As the project was assessed as high risk due to its relevance to Aboriginal and Torres Strait Islander people (thus requiring review by the full HREC), it required supplementary information to support participant risk assessment. Initially, the approving HREC suggested the project required Site Specific Assessment (SSA) approval from each of the 18 HHSs from which eligible participants

could be recruited. However, on engagement with each HHS, their HRECs advised SSA approval was not necessary as participation was voluntary. Following this advice, the approving HHS HREC accepted an SSA waiver, which was obtained on 24 October 2024.

QAIHC internal processes required the invitation letter to Member ACCHOs (inviting them to participate in the research) be sent by the Executive Assistant on behalf of the CEO of QAIHC, neither of whom were listed on the ethics approval as investigators, or on the funding agreement as members of the research team. Invitation letters were sent to the senior executive of each ACCHO noting the responsible person for the research project (CIA Associate Professor Pratt), and inviting them to nominate a person to be contacted and invited to participate in the project. Invitation letters to the HRECs were sent individually to the generic email addresses for each HREC. The chair and co-ordinator for each HREC was invited to participate in the project.

Since commencement of the project, the NHMRC updated the National Statement on Ethical Conduct in Human Research (2025). In accordance with the recently-revised statement, HREC review pathways have changed such that this project may have been assessed as lower risk, potentially reducing burden for the reviewing HREC and investigator team.

QAIHC Member Research Workshop

Complications arose due to the COVID-19 pandemic. This included maintaining a commitment to the aims and objectives of the study, while addressing Member engagement barriers and stretching funding over a protracted timeline. To meet the minimum deliverables of the project, the investigator team hosted a QAIHC Members Research Workshop in Brisbane, Australia, rather

than the originally planned series of ACCHO engagements across Queensland. This change in protocol supported facilitation of yarning circle sessions in a single event instead of multiple events in many locations.

HREC Focus Groups

The CIA and project manager originally planned to travel Queensland facilitating focus groups. It was hoped community-hosted events would allow opportunity for relationship and capacity building, on top of ethics committee engagement. Recognising the constrained timeline, it was decided to proceed with online meetings using Microsoft Teams to engage with as many HRECs as possible. This route would also support thematic analysis, the consolidation of results, as well as reporting research recommendations and findings.

Recommendations and Conclusions

From the stakeholder engagements across Queensland, the following key learnings were noted:

1. Research is central to CQI and an integral part of the core business of the ACCHO sector.
2. There is a genuine interest to support the establishment of an independent QATSIHREC.
3. There is a preference that the suggested research ethics governance entity (i.e. QATSIHREC) be housed in the ACCHO sector with a statewide remit.

Recommendations

In alignment with the aforementioned learnings the following actions are recommended:

1. Resourcing to support the establishment of QATSIHREC. Development of a research strategy, on behalf of the sector, to support ACCHOs responding to and leading community driven research.

Conclusions

Aboriginal and Torres Strait Islander research ethics governance processes in Queensland are important, and in need of improvement. There were slight differences in the emphasis placed on concepts and themes expressed by ACCHOs and HREC participants in terms of importance and implications for the expression and suggested implementation for a real-world environment.

Conversations among HREC participants emphasised the importance of ethics review processes, and assessment of research from a beneficence and community buy-in perspective, whereas ACCHOs emphasised the importance of alignment with community values, community driven research and using research to support the core business of healthcare for health outcomes.

Both ACCHO and HREC representatives described a need for reform in all aspects of Aboriginal and Torres Strait Islander research, research governance, ethics and ethics governance. Research ethics governance is complex and finding

ways to improve processes requires stakeholders working together in innovative and complementary ways.

A QATSIHREC would serve Queensland in better aligning it with other jurisdictions, and investigating the business case is a worthy resource allocation.

Development of a research strategy would support ACCHOs to respond to and lead community driven research, as well as meet expectations of the research, healthcare and policy sector. Such a strategy should seek to build the capacity and capability of ACCHOs and empower community-informed, ACCHO-led, community-driven research that supports healthcare reform and CQI.

The role of Aboriginal and/or Torres Strait Islander peoples in determining research ethics governance architecture that aligns with our ways of knowing, being and doing must be recognised and respected. Establishing a QATSIHREC would be a worthy but significant undertaking, requiring a diverse set of expertise in research, ethics and the governance of both. Such expertise must be coupled with an unapologetic commitment to Aboriginal and Torres Strait Islander community-led research for the benefit of Aboriginal and Torres Strait Islander communities.

Appendices

Appendix 1: ACCHO Survey

Appendix 2: HREC Survey

Appendix 3: QAIHC Members Research Workshop Agenda

Appendix 4: HREC Yarning Circle Agenda

Appendix 5: Yarning Circle Topics and Prompts

Appendix 6: Mentimeter Questions and Prompts



‘Research Our Way’: Closing the gap in Aboriginal and Torres Strait Islander human research ethics governance in Queensland



Please indicate the geographic region that best describes the catchment for your Aboriginal Community Controlled Health Organisation:

- ☐ Far North Queensland (including Cape York and Torres Strait)
- ☐ North Queensland (including Gulf of Carpentaria)
- ☐ Central Queensland (including Central West)
- ☐ South East Queensland (including Sunshine and/or Gold Coast)
- ☐ South West Queensland (including Darling Downs)
- ☐ Statewide

1. Do you receive requests for research involving Aboriginal and/or Torres Strait Islander peoples?

- ☐ Yes / ☐ No

2. Does your organisation have a process for managing requests to support and/or participate in research?

- ☐ Yes / ☐ No

3. Does your organisation have designated staff members to receive and review research requests?

- ☐ Yes / ☐ No

4. Is your organisation involved in the co-design of research projects?

- ☐ Yes / ☐ No

5. Does your organisation actively promote and encourage the involvement of Aboriginal and/or Torres Strait Islander peoples in research?

- ☐ Yes / ☐ No

6. Would your organisation be interested in participating in a QAIHC Research Camp for ACCHOs to discuss your preferences and experiences of research in Queensland?

- ☐ Yes / ☐ No

7. As part of the QAIHC Research Camp, would you be interested in attending a focus group discussion about research ethics governance?

- ☐ Yes / ☐ No

‘Research Our Way’: Closing the gap in Aboriginal and Torres Strait Islander human research ethics governance in Queensland



8. We would welcome any additional feedback if you would like to provide it:

This study will be conducted in full conformance with the NHMRC National Statement on Ethical Conduct in Research and has approval from Darling Downs Hospital and Health Service (DDHHS) Human Research Ethics Committee.

If you would like to discuss your rights as a participant or to discuss the conduct of the study, please contact the Research Ethics and Governance Officer, DDHHS HREC on 07 4616 6461. All matters will be dealt with confidentially.

'Research Our Way': Closing the gap in Aboriginal and Torres Strait Islander human research ethics governance in Queensland



Please indicate the geographic regions that best describe the catchment from which your Human Research Ethics Committee (HREC) receive ethics applications (select all that apply):

- ☐ Far North Queensland (including Cape York and Torres Strait)
- ☐ North Queensland (including Gulf of Carpentaria)
- ☐ Central Queensland (including Central West)
- ☐ South East Queensland (including Sunshine and/or Gold Coast)
- ☐ South West Queensland (including Darling Downs)
- ☐ Statewide
- ☐ Nationwide
- ☐ Other

1. Do you receive applications for research **specifically involving Aboriginal and Torres Strait Islander peoples?**

- ☐ Yes / ☐ No

2. Please Indicate the processes that your HREC uses in making decisions about research proposals involving Aboriginal and/or Torres Strait Islander people (select all that apply):

- ☐ Our Committee is an Aboriginal and/or Torres Strait Islander HREC
- ☐ We refer to an interstate Aboriginal and/or Torres Strait Islander HREC
- ☐ We refer to an Aboriginal and/or Torres Strait Islander Ethics Governance group (e.g. HREC subcommittee, community jury, etc)
- ☐ We have Aboriginal and/or Torres Strait Islander representation on our HREC, specifically to assist in the review of proposals for research involving Aboriginal and/or Torres Strait Islander people
- ☐ We refer proposals for research involving Aboriginal and/or Torres Strait Islander people to an Aboriginal and/or Torres Strait Islander person external to our committee
- ☐ Our current process does not avail review by an Aboriginal and/or Torres Strait Islander person
- ☐ We actively promote and encourage researchers to become familiar with, address and comply with the National Health and Medical Research Council (NHMRC) Ethical guidelines for research with Aboriginal and Torres Strait Islander peoples
- ☐ We actively promote and encourage researchers to become familiar with, address and comply with the Australian Institute of Aboriginal and Islander Studies (AIATSIS) Code of Ethics for Aboriginal and Torres Strait Islander Research
- ☐ Other, please specify:

3. If you refer to an Aboriginal specific Ethics Committee or Governance group, please name the Committee to whom you refer:

Appendix 2: HREC Survey (continued)

‘Research Our Way’: Closing the gap in Aboriginal and Torres Strait Islander human research ethics governance in Queensland



4. Does your HREC avail its members the opportunity for training in the application of ethical standards for research involving Aboriginal and/or Torres Strait Islander people?

☐ Yes / ☐ No

5. Would you be interested in receiving updates about this project?

☐ Yes / ☐ No

6. Would you be interested in participating in a focus group with other members of Human Research Ethics Committees, discussing their experiences of reviewing ethics clearance applications for research involving Aboriginal and Torres Strait Islander people?

☐ Yes / ☐ No

8. We would welcome any additional feedback if you would like to provide it:

This study will be conducted in full conformance with the NHMRC National Statement on Ethical Conduct in Research and has approval from Darling Downs Hospital and Health Service (DDHHS) Human Research Ethics Committee.

If you would like to discuss your rights as a participant or to discuss the conduct of the study, please contact the Research Ethics and Governance Officer, DDHHS HREC on 07 4616 6461. All matters will be dealt with confidentially.

Appendix 3: QAIHC Members Research Workshop Agenda

MEMBERS

Research Workshop

MEANJIN – BRISBANE | 28 APRIL 2025



AGENDA

Time	Topic	Speaker
8:00 am	Registration and Shared breakfast (30 mins)	
8:30 am	Welcome, Acknowledgement of Country and Introductions (10 mins)	Greg Pratt
8:40 am	Background to REG project (20 mins)	Greg Pratt Prof. Ray Mahoney
9:00 am	Introduction to Research, Ethics, and Ethics Governance (1 hr)	Prof. Yvonne Cadet-James Dr. Michael Doyle Prof. Ray Mahoney
10:00 am	Morning Tea (15 mins)	
10:15 am	Yarning Circle 1 – Reflecting on the experiences of the Sector (90 mins)	Greg Pratt Tegwen Howell
11:45 am	Refreshment Break (15 mins)	
12:00 pm	Yarning Circle 2 - Reflecting on the preferences of the Sector (90 mins)	Greg Pratt Tegwen Howell
1:30 pm	Lunch (30 mins)	
2:00 pm	Summary of Yarning Circle Discussions (45 mins)	Greg Pratt Tegwen Howell
2:45 pm	Confirmation of Recommendations and Actions (15 mins)	Greg Pratt Prof. Ray Mahoney
3:00 pm	Closing Address (15 mins)	Greg Pratt
3:15 pm	Afternoon Tea/Networking	

Appendix 4: HREC Yarning Circle Agenda

Agenda

- Welcome & Acknowledgement
- Introductions
- Background to the REG project
- Yarning Circle 1: Reflecting on the experiences of HRECs
- Yarning Circle 2: Reflecting on the preferences of HRECs
- A Commitment to Communication & Future Directions

0905

QAIHC

Appendix 5: Yarning Circle Topics and Prompts

QAIHC Members Research Workshop – Yarning Circle Topics and Prompts

Yarning Circle Session 1

Topic: “Reflecting on the experiences of the Sector

Prompts:

- How do you define Aboriginal and Torres Strait Islander Health Research?
- What does your involvement in health research currently look like?
- What does community involvement in research currently look like?
- Is it Ok to say NO to research and how do we do that?

Yarning Circle Session 2

Topic: “Reflecting on the preferences of the Sector”:

Prompts:

- What is needed to ensure Indigenous self-determination and sovereignty in research?
- What is needed to ensure Indigenous leadership and research governance?
- What is needed to ensure Indigenous self-determination in ethics?
- What is needed to support Indigenous self-determination and sovereignty in Ethics Governance?

HREC Focus Groups – Yarning Circle Topics and Prompts

Yarning Circle 1

Topic: “Reflecting on the experiences of HRECs”:

Prompts:

- How do you define Indigenous Health Research?
- How does your HREC determine if a project is relevant to Indigenous peoples?
- What processes does your HREC use to review applications for research of relevance to Aboriginal and/or Torres Strait Islander peoples?

Yarning Circle 2

Topic: “Reflecting on the preferences of HRECs”:

Prompts:

- What is needed to ensure Indigenous self-determination and sovereignty in research?
- What is needed to ensure that Indigenous values inform research?
- What is needed to support Indigenous self-determination and sovereignty in Ethics Governance?

Appendix 6: Mentimeter Questions and Prompts

Likert Scale Questions:

Rate statements from strongly agree to strongly disagree.

Aboriginal and Torres Strait Islander Research:

- Responds to a community identified concern
- Emphasises Aboriginal and Torres Strait Islander ways of being, knowing and doing
- Focuses on a concern of significance to Aboriginal and Torres Strait Islander people
- Led by an Aboriginal and/or Torres Strait Islander person as chief investigator
- Researcher Driven
- Community Driven

Researchers Typically:

- Involve community in research.
- Use research funding to pay for community-based researchers based in ATSI CCHOs
- Ask how they can use their skills to help ATSI CCHOs to answer a community identified health concern
- Expect ATSI CCHOs to provide in-kind support to research projects
- List ATSI CCHOs as partner organisations and ATSI CCHO staff as chief investigators on research proposals

Separate and Individual Questions:

- Community is generally well informed about research.
- It is a responsibility of researchers to involve and inform community about research.
- It is a responsibility of ATSI CCHOs to involve and inform community about research.
- Aboriginal and Torres Strait people have the right to participate in all research.
- All research should articulate a responsibility for benefiting Aboriginal and Torres Strait Islander people.
- Research of significance to Aboriginal and Torres Strait islander people should demonstrate adherence with their ways of being, knowing and doing.
- Queensland needs an Aboriginal and Torres Strait Islander Human Research Ethics Committee.
- All HRECs are responsible for being able to receive and review all applications for ethics clearance for all research.
- Existing HRECs do not have the capability to govern ethics for research of relevance to Aboriginal and Torres Strait Islander people of Queensland.

Predefined Closed Ended Questions

yes, no, sometimes... it depends

- It is ok to say NO to research?
- Is it reasonable that data be used (with the appropriate permissions) for a public health benefit?

Open-Ended Questions:

- Are there alternatives to a Queensland Aboriginal and Torres Strait Islander HREC that would support self-determination in ethics governance?
- What factors most influence your deciding **not** to support a research project?
- How does the ATSI CCHO sector work with community to identify community health concerns?
- What do you recommend researchers do to work with community to develop proposals to respond to community-identified health concerns?
- How is a shared responsibility for the different parts of a research project best reflected in terms of leadership, partnership and championship?
- How would you suggest that we balance the needs and preferences of individuals and the rights of the collective?

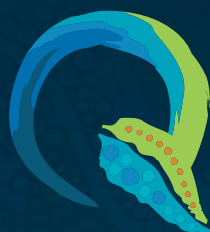
Ranking Questions

Rank in order of most frequent request type (first being most requested and last being the least requested):

- Collecting data and recruiting participants
- Providing letters of support
- Developing draft research proposal
- Consulting with community for the research
- Analysing data
- Reporting and disseminating results

References

1. AIATSIS, *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research*. 2020, Australian Institute of Aboriginal and Torres Strait Islander Studies: Canberra.
2. Anderson, I., *Ethics and health research in Aboriginal communities*, in *Ethical intersections*. 2019, Routledge. p. 153–165.
3. Askitopoulou, H., *The Hippocratic principle “to help or at least to do no harm”*. *Transfus Clin Biol*, 2024. **31**(3): p. 174–180.
4. Bainbridge, R., et al., *No one’s discussing the elephant in the room: contemplating questions of research impact and benefit in Aboriginal and Torres Strait Islander Australian health research*. *BMC Public Health*, 2015. **15**: p. 696.
5. National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research*, N.H.a.M.R. Council, Editor. 2025, Australian Research Council and Universities Australia: Canberra.
6. Finlay, S.M., M. Doyle, and M. Kennedy, *Aboriginal and Torres Strait Islander Human Research Ethics Committees (HRECs) are essential in promoting our health and wellbeing*. *Public Health Res Pract*, 2023. **33**(2).
7. Burchill, L.J., et al., *Ethics guidelines use and Indigenous governance and participation in Aboriginal and Torres Strait Islander health research: a national survey*. *Med J Aust*, 2023. **218**(2): p. 89–93.
8. Collis, F. and M. Kennedy, *Keeping research on track? Aboriginal and Torres Strait Islander accounts of ethical conduct in health and medical research*. 2025.
9. Miller A, W.R., & Wolski B., *Future Direction into the Ethical Review of Health Research Involving Aboriginal and Torres Strait Islander Peoples in Queensland - Roundtable Report*. 2014, Griffith University: Melbourne.
10. Fletcher, F.E., et al., *Addressing Anti-Black Racism in Bioethics: Responding to the Call*. *Hastings Cent Rep*, 2022. **52 Suppl 1**(Suppl 1): p. S3–s11.
11. Health, A. and M.R.C.o. NSW, *NSW Aboriginal health ethics guidelines: key principles*. 2023.
12. Kennedy, M., et al., *Human research ethics committee processes and practices for approving Aboriginal and Torres Strait Islander health research: a mixed methods study*. *Medical journal of Australia*, 2025. **222**: p. S34–S41.
13. Stuart, L. and N. Howell, *The Time Has Come: Indigenous Peoples Worldwide Must Now Exercise Their Human Rights and Take Full Control Over Their Data Sovereignty Rights*. *Health Promot J Austr*, 2025. **36**(3): p. e70055.
14. Collis, F., et al., *Aboriginal and Torres Strait Islander community experiences and recommendations for health and medical research: a mixed methods study*. *Med J Aust*, 2025. **222 Suppl 2**: p. S6–S15.
15. Kennedy, M. and J. Bryant, *Ethics in Aboriginal and Torres Strait Islander health research: discussion paper*. 2024.
16. McGuffog, R., et al., *Murru Minya—informing the development of practical recommendations to support ethical conduct in Aboriginal and Torres Strait Islander health research: a protocol for a national mixed-methods study*. *BMJ open*, 2023. **13**(2): p. e067054.
17. The Victorian Aboriginal Community Controlled Health Organisation, *marra ngarrgoo, marra goorri: the victorian aboriginal health, medical and wellbeing research accord*. 2023: Victoria State Government.



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