



BMJ Open *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

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ABSTRACT

Introduction Conducting ethical and high-quality health research is crucial for informing public health policy and service delivery to reduce the high and inequitable burden of disease experienced by Aboriginal and Torres Strait Islander people. Ethical guidelines and principles specifically for health research with Aboriginal and Torres Strait Islander people have been developed for use since 1987. However, there has been limited examination of how these are being applied to the conduct of research.

Methods and analysis *Murru Minya* will be a large-scale national study to examine the implementation of ethical processes in Aboriginal and Torres Strait Islander health research. A mixed-methods design will be used in four *baarra* (steps). The first three *baarra* will collect knowledge, experiences and wisdom from three key groups: Aboriginal and Torres Strait Islander communities, research academics, and Human Research Ethics Committees using online surveys, yarning, and semistructured interviews. This knowledge will inform the final *baarra* of developing a set of practical recommendations to support ethical conduct in Aboriginal and Torres Strait Islander health research into the future.

Ethics and dissemination Ethical approval for this research project has been granted by National, State and Territory Human Research Ethics Committees. This research has been developed in collaboration with Aboriginal and Torres Strait Islander researchers, Aboriginal Community Controlled Health Organisation representatives, Aboriginal community members, the National Health Leadership Forum, and Aboriginal and Torres Strait Islander research team. The knowledge translation plan will be integrated and revised throughout the project as partnerships and engagement with Aboriginal and Torres Strait Islander communities continue. All findings will be shared with peak Aboriginal research bodies and Aboriginal and Torres Strait Islander communities in ways that are meaningful to them.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ *Murru Minya* will be the first national review of experiences with Aboriginal and Torres Strait Islander health research implementation, led by Aboriginal and Torres Strait Islander researchers.
- ⇒ The mixed-methods design allows for comprehensive insight into Aboriginal and Torres Strait Islander health research, across various stakeholders (Aboriginal and Torres Strait Islander communities, academics and Human Research Ethics Committee members) to inform future practice.
- ⇒ *Murru Minya* upholds Indigenous governance, provided by the National Health Leadership Forum and an Aboriginal and Torres Strait Islander research team.
- ⇒ *Murru Minya* is not intended to be representative; the aim of the study is to understand the ethical conduct of research across diverse groups and experiences.
- ⇒ Yarning circles with communities and Human Research Ethics Committee members may be impacted by COVID-19.

INTRODUCTION

Epistemologies, or systems of knowledge, that are privileged in euro-centric western institutions including academic journals, universities and government agencies have caused harm to Aboriginal and Torres Strait Islander people.^{1–3} Since colonisation, research has been used as a tool to dehumanise Aboriginal and Torres Strait Islander people under the false narrative of Terra Nullius.^{4–6} There is ongoing evidence of contemporary unethical research conducted on Aboriginal and Torres Strait Islander peoples, such as taking

samples of children's blood, without consent, to measure and monitor health conditions.⁷ Such research has largely excluded Aboriginal and Torres Strait Islander peoples' oversight and guidance, which is a likely factor for the limited improvements in the health and well-being of Aboriginal and Torres Strait Islander people to date.²

The establishment and implementation of ethical frameworks and guidelines have attempted to ensure Aboriginal and Torres Strait Islander values are upheld in research. In 1987, The National Aboriginal & Islander Health Organisation developed the first guidelines on ethical responsibilities in Aboriginal and Torres Strait Islander health research.³ The National Health and Medical Research Council's (NHMRC) *Values and Ethics* from 2003 replaced the 1991 document *Guidelines on ethical matters in Aboriginal and Torres Strait Islander Health Research*.⁸ In 1999, the New South Wales Aboriginal Health and Medical Research Council (AH&MRC) produced its first *Guidelines for Research into Aboriginal Health*. Since this time, national and state-based ethical research guidelines have been published^{9–12} and reviewed.¹³ These ethical guidelines represent collaborative endeavours that involved researchers, Aboriginal and Torres Strait Islander community members and peak bodies. An example of a peak body, or leading body, in Aboriginal health includes the National Aboriginal Community Controlled Health Organisation, who represent 144 Aboriginal Community Controlled Health Organisations (ACCHOs) across the country, and acts to provide advice on community-developed and driven health solutions to the federal government. Concurrently with the development of guidelines, Aboriginal-specific state-based Human Research Ethics Committees (HRECs), such as the Western Australian Aboriginal Health Ethics Committee, have been established and registered with NHMRC to review research and ensure compliance to the above-mentioned guidelines.¹⁴

All guidelines are based on the fundamental principles that research must be safe, respectful, responsible, high quality and of benefit to Aboriginal and Torres Strait Islander people.⁸ In 2019, the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) undertook a comprehensive review of the Guidelines for Ethical Research in Australian Indigenous Studies 2012.^{10 15} The review's objective was to develop a deeper understanding of ethical conduct via a Code of Ethics embedded in Aboriginal and Torres Strait Islander worldviews.¹⁵ The review process raised concerns regarding compliance, enforceability and institutional responsibility for the Code of Ethics.¹⁵

A previous evaluation of NHMRC ethical research guidelines, conducted by members of the research team, asserted that 'Aboriginal influence and practices (ie, right way to research) can improve the entire sector (research)'.¹³ A growing cohort of Aboriginal and Torres Strait Islander researchers continue to explore areas of research design, development and implementation in an effort to improve research conduct. Examples of such

bodies of work include research principles for Aboriginal and Torres Strait Islander health research,¹⁶ assessing impact,² articulating ethical practice in partnership with communities,^{17–22} Aboriginal governance,²⁰ policy,^{23–25} Indigenous methodologies,^{26 27} appropriate research reporting²⁸ and the use of data.^{29 30} While significant efforts have been placed on developing culturally appropriate research guidelines for Aboriginal and Torres Strait Islander health in Australia, there is limited evidence about how ethics processes have been operationalised in research practice. This knowledge gap is crucial to improving the quality and quantity of research to achieve health equity.

To date, there has been no comprehensive evaluation of the implementation of ethical guidelines in Australia. It is therefore unknown how the principles for the ethical research conduct have been implemented by researchers, the processes that support and/or impede the implementation of ethical principles, and whether research experiences of Aboriginal and Torres Strait Islander communities have improved as result of these guidelines. The Closing the Gap campaign has called for structural reform, including an Aboriginal and Torres Strait Islander-led research agenda.³¹ It is therefore imperative and timely to reflect on how Aboriginal and Torres Strait Islander health research has been, and continues to be, conducted. A multifactorial investigation of influences on research conduct, which privileges the voices and experiences of Aboriginal and Torres Strait Islander people and communities, is needed. This investigation will lead to the development of research principles and practice recommendations.

Objectives

This project involves a comprehensive review of Aboriginal and Torres Strait Islander health research, using a conceptual framework *Yindymarra*, to develop a set of practical recommendations for ethical research adherence (see figure 1). *Yindymarra* is a Wiradjuri cultural



Figure 1 *Yindymarra* conceptual framework for the proposed research. AH&MRC, Aboriginal Health and Medical Research Council.

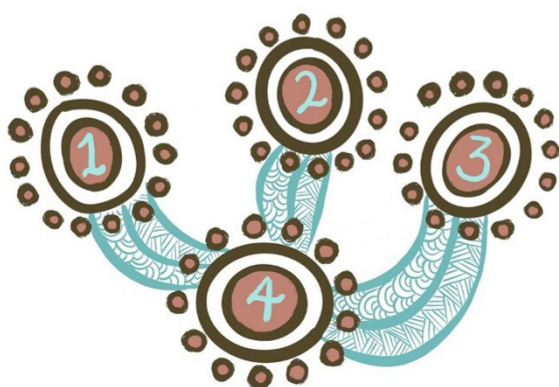


Figure 2 Overview of *baarra* (steps).

practice meaning ‘to conduct yourself with honour and respect, to do things slowly and thoughtfully’. The lead researcher is a Wiradjuri woman and has developed the conceptual framework for this project building on key guidelines for Aboriginal and Torres Strait Islander health research conduct, depicted in the outside circles. Aboriginal ontology (being), epistemology (knowing) and axiology (doing) are privileged through an Indigenous standpoint and research methodologies^{32 33} as depicted in the middle circle. The individual studies of this project are represented in the centre. This project acknowledges the importance of prior ethical guidelines and the substantial work that has contributed to their development and refinement. This project, through *Yindymarra*, will *winhang-a-duri-nya* (reflect) on how these ethical guidelines have been used in research processes. Through the development of recommendations, more informed research planning can occur, which will maximise efficiency in research consultation and implementation, increasing the potential for positive research outcomes for Aboriginal and Torres Strait Islander people.

The project will undertake four *baarra* (steps) to achieve *gulbnha* (knowledge) (see figure 2). The first three *baarra* will collect knowledge, experiences and wisdom from three key groups: Aboriginal and Torres Strait Islander communities, research academics and HRECs, to inform the final *baarra* of developing a set of practical recommendations for the future.

This project aims to:

1. Investigate ACCHOs’ involvement in health research and identify, through the voices and experiences of Aboriginal and Torres Strait Islander communities, their perceptions of ethical practice.
2. Explore, among academics conducting Aboriginal and Torres Strait Islander health research, their perceptions of the barriers and enablers to conducting Aboriginal and Torres Strait Islander health research, and adhering to ethical principles.
3. Understand, from the perspectives of HRECs, their processes for overseeing and approving Aboriginal and Torres Strait Islander health research and their

perceptions of researcher adherence to ethical principles.

4. Develop a set of practical recommendations, which are nationally endorsed by Aboriginal and Torres Strait Islander health experts, researchers, and Aboriginal and Torres Strait Islander communities, to support the implementation of high-quality and ethical Aboriginal and Torres Strait Islander health research.

METHODS

Research team

Research methodology and research team members’ worldviews influence perspectives, values, how the *Murru Minya* study was created, and how it will be conducted, analysed and interpreted.^{34 35} The study was conceptualised and will be led by MK (Wiradjuri woman), in partnership with other Aboriginal and Torres Strait Islander researchers: AB, MW, JH, SJE, CC, MW, KK, PO and KEG who are located across the country. Our team brings decades of experience, expertise and recognised leadership in Aboriginal and Torres Strait Islander health and well-being. Our expertise includes, but are not limited to, maternal and reproductive health (CC, SJE), Aboriginal Community Controlled Health (MK, FC, PO, MW), risk factors and chronic disease (AB, SJE), renal care (JH), early intervention and hearing (KK, SJE, CC), epidemiology (KEG, SJE) and inequality (MW). Our team has expertise in scientific methods including data sovereignty and governance (KEG, MW), qualitative research (MK, CC), quantitative research (JB, MW, BH, KEG, CC, KK, AB, SJE), clinical research (PO, AB, JH, KK), co-design interventions (CC, JH, MK, SJE) and implementation science (CC, MK, JB, BH, KG), as well as extensive expertise in developing and evaluating Aboriginal and Torres Strait Islander health research strategies, evaluations and frameworks. This project is Aboriginal and Torres Strait Islander led and provides guidance for non-Indigenous researchers working on the project (RM, JB, BH).

Patient and public involvement

Oversight of the research will be provided by the National Health Leadership Forum (NHLF) and an Aboriginal and Torres Strait Islander investigative team. The NHLF was considered the most appropriate governance committee for this project as they represent a broad scope of health professions and are inclusive of the Chief Executive Officers (CEOs) of peak bodies. One key priority of the NHLF is accountability within the health system, which includes research, ethics and funding. The NHLF will provide national project governance to ensure that the research is appropriate and meaningful to all of the Aboriginal and Torres Strait Islander communities involved. Consultation with the NHLF will occur biannually throughout the project (from 2021 to 2024).

Study components

A mixed-methods design will be used incorporating three *baarra*, each involving a survey and semistructured

Table 1 Ethical guidelines for Aboriginal and Torres Strait Islander research

Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities: guidelines for researchers and stakeholders ¹¹	Keeping research on track II ⁴²	AH&MRC ethical guidelines: key principles (2020) V.2.0 ⁹	AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander research ¹⁰	South Australian Aboriginal health research accord ¹²
1. Spirit and integrity	1. Building relationships	1. Net benefits for Aboriginal people and communities	1. Indigenous self-determination	1. Priorities
2. Cultural continuity	2. Developing the research idea	2. Aboriginal community control of research	2. Indigenous leadership	2. Involvement
3. Responsibility	3. Developing the project and seeking agreement	3. Cultural sensitivity	3. Impact and value	3. Partnership
4. Reciprocity	4. Data collection	4. Reimbursement of costs	4. Sustainability and accountability	4. Respect
5. Respect	5. Analysing the data and making sense of the findings	5. Enhance Aboriginal skills and knowledge		5. Communication
6. Equity	6. Report writing			6. Reciprocity
	7. Sharing and translating the results into action			7. Ownership
	8. Learning from experience			8. Control
				9. Knowledge translation

AH&MRC, Aboriginal Health and Medical Research Council; AIATSIS, Australian Institute of Aboriginal and Torres Strait Islander Studies.

interviews and/or yarning circles. The data collected in phase 1 will inform the development of practical recommendations in *baarra* 4. The study period is from June 2021 through to December 2024.

Measure development

The surveys and interview/yarning circle guides were developed following the conduct of a review of the peer-reviewed literature, review of ethical guidelines and input from the Aboriginal and Torres Strait Islander research team and ACCHO representatives. Survey items were pilot tested and amended according to Aboriginal and Torres Strait Islander researchers and communities' feedback to ensure they were culturally appropriate and acceptable. The contents of the surveys and interview guides are described below (within each *baarra*). For copies of the surveys and interviews, please see online supplemental file 1.

An overview of the currently available ethical guidelines for researchers working in Aboriginal and Torres Strait Islander health research and their key principles can be found in [table 1](#). The research team explored the key areas for investigation across these ethical guidelines relevant for this research project and established 13 key areas used in the first three *baarra*. The key areas are outlined in [table 2](#) with reference to the principles

in each of the four ethical guidelines. Each survey, interview and yarning circle will explore these key areas from the perspective of communities, researchers and ethics committee members.

COVID-19 and potential impact

All aspects of the research will be conducted in line with community protocols. It is anticipated that the interviews for *baarra* 2 will be conducted over zoom and have minimal risk of impact. *Baarra* 1 and 3 will have the opportunity to conduct any yarning circles and interviews over zoom if this is the preferred method due to COVID-19 outbreaks. Any face-to-face meeting, interview or yarn will follow university and community protocols. The impact of COVID-19 on researchers' conduct of research in 2020–2022 will be considered and navigated as guided by our participants.

Baarra 1: exploration of Aboriginal and Torres Strait Islander communities' experience with health research

Baarra 1 will involve: (1) an online cross-sectional survey of CEOs and/or senior management of ACCHOs; and (2) qualitative yarning circles with relevant community stakeholders, including ACCHO staff, patients and community members.

Table 2 Key areas for Aboriginal and Torres Strait Islander engagement in health research

Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities: guidelines for researchers and stakeholders ¹¹											AH&MRC ethical guidelines: key principles (2020) v2.0 ⁹				AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander research ¹⁰				South Australian Aboriginal health research accord ¹²			
	Keeping research on track II ⁴²										AH&MRC ethical guidelines: key principles (2020) v2.0 ⁹				AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander research ¹⁰				South Australian Aboriginal health research accord ¹²			
Aboriginal community engagement in prioritising research ideas and developing the research questions	1	3	4	6	1	2	3	1	2	3	1	2	3	1	2	3	4	1	2			
Aboriginal governance, advisory and decision-making on the project	1	2	5	6	2			1	2					1	2	3	4	1	2			
Adopt Indigenous data sovereignty and governance principles	1	3	5	6	1	4	7	1	2					2	3	4		1	2			
Research agreements with Aboriginal communities	1	5	6		3			1	2					1	2	3	4	1	2			
Embedding opportunities in the research for capacity building for Aboriginal communities	1	4	6		4			5										1	6			
Embedding opportunities in the research for capacity building of the research team for research with Aboriginal communities (ie, developing cultural capabilities)	1		2											1				1	2			
Community engagement in research implementation	1	3	4	6	4			2						1	2	4		1	2			
Having Aboriginal project team members	1		6		4			2	5					1	2	4		1	2			
Community engagement in the analysis and interpretation of findings	1	2	3	6	5	6		2						1	2	4		1	2			
Reimbursement of costs	1							4										3	6			
Disseminating results to the community	1		6		7			5										1	2			
Involve community members as coauthors on publications and co-presenters on presentations	1	5	6		6			2	5					1	2	4		1	2			
Translating the results into action	1		6		7	8								1	2	3		1	2			
Numbers presented in this table correspond to the numbered key areas from each guideline presented in table 1 . AH&MRC, Aboriginal Health and Medical Research Council; AIATSIS, Australian Institute of Aboriginal and Torres Strait Islander Studies.																						

ACCHOs are community-driven, primary healthcare providers for Aboriginal and Torres Strait Islander people. ACCHOs, through their provision of holistic, comprehensive and culturally informed care, highlight the social determinants of health and health inequity experienced by Aboriginal and Torres Strait Islander communities.³⁶ They are also a primary employer of Aboriginal and Torres Strait Islander people and regularly sought to participate in the implementation of Aboriginal and Torres Strait Islander health research.

Survey

All ACCHOs in Australia are eligible to participate. The CEO and/or senior management of various ACCHOs will receive an email and hard copy invitation including a Participant Information Sheet, a link to the online survey, hard copy survey, a brochure with information on the project and links to project website for more information. The survey will also be promoted through our *Murru Minya* website. Additionally, we will do a targeted recruitment through health services, since health services play a critical role in improving the health and well-being of Aboriginal and Torres Strait Islander communities. Participants will be asked to provide descriptive characteristics of their practice including type of service, area postcode and the importance of different types of engagement with research (based on the key areas identified in [table 2](#)). A previous state-based study obtained consent rates of 66% when recruiting Aboriginal Community Controlled Health Services.³⁷ Based on this study, we anticipate a minimum of 30 and up to 90 ACCHOs to consent to the survey component of the study.

Yarning circles

At the end of the survey, participants will be asked to indicate their interest in hosting yarning circle/s in their community. This will include separate yarns for staff and Aboriginal and Torres Strait Islander patients/community members. Yarning will be led by Aboriginal and Torres Strait Islander members of the research team in partnership with the consenting Aboriginal service. The yarning process will incorporate social yarning, research topic yarning, collaborative yarning and concluded with sharing a meal.²⁶ Only the collaborative yarning process will be used for data collection, with social and research topic yarning used to build relationships and trust with the communities involved in the study and obtain informed consent. Up to 20 ACCHOs will be recruited to participate in yarning circles, with up to three from each state or territory. If more than three ACCHOs within each state/territory express interest, the research team will seek to balance urban and rural/remote communities. With 5–10 staff and 10 community members at each service, there will be a maximum of 400 participants.

Baarra 2: academic's perceptions of undertaking ethical research

Baarra 2 will involve an (1) online cross-sectional survey and (2) semistructured qualitative interviews with researchers (including Indigenous researchers and

non-Indigenous researchers) who have conducted and/or published research in Aboriginal and Torres Strait Islander health.

Survey

All researchers who self-identify as working in Aboriginal and Torres Strait Islander health are eligible to participate. Potential participants will be identified through publications in Aboriginal and Torres Strait Islander health using publicly available contact information listed on publications. The publications are based on publications in Aboriginal and Torres Strait Islander health reported in a recent review,³⁸ from 2015 to present. The survey will also be promoted through peak partnerships such as the Lowitja Institute, NHMRC, AH&MRC, and the research team's networks and social media channels encouraging all researchers working in Aboriginal and Torres Strait Islander health research to participate. Participants will be asked to provide demographics, descriptive characteristics of their research career and their experiences of the ethics process. Participants will also be asked about the (a) importance of different types of Aboriginal and Torres Strait Islander engagement with research, (b) how well they engage Aboriginal and Torres Strait Islander communities in their research, and (c) how well they perceive other researchers to engage Aboriginal and Torres Strait Islander communities in research (based on the key areas identified in [table 2](#)). A large sample of researchers will be recruited, with a minimum of 300 participants and a maximum of 2000 participants. A consent rate of 50% of those approached is expected based on previous studies among researchers using similar recruitment methods.³⁹

Interviews

At the end of the survey, participants will have the option to indicate their interest in participating in a one-on-one interview. Participants who indicate their interest in participating in an interview will be purposively sampled to allow a diverse sample of researchers and experiences, including Indigenous researchers and non-Indigenous researchers, and individuals representing a variety of different career stages.

Interviews will be guided by an interview schedule and will take approximately 30–60 min to complete. Questions will include perceptions of their research practice and experiences including perceived barriers or enablers for conducting ethical Aboriginal and Torres Strait Islander research. We will analyse the data in correspondence with ethical research guidelines and frameworks (see [table 2](#)). Interviews will be undertaken until saturation of themes is achieved, which is expected to require approximately 20–30 interviews.

Baarra 3: the process of Aboriginal and Torres Strait Islander research from the perspective of HRECs

To better understand the ethics process when conducting Aboriginal and Torres Strait Islander research, HREC members will be invited to participate in: (1) an online

survey and (2) semistructured qualitative interviews in *baarra 3*.

Survey

Current and past members (within the last 5 years) of an NHMRC-approved HREC will be eligible to participate. HRECs will be contacted by the research team and asked to distribute invitations to participate to all current and past (in the last 5 years) committee members. Advertisement of the survey will also be provided through the *Murru Minya* website and partnered stakeholders (eg, the Lowitja Institute, National Aboriginal Community Controlled Health Organisation). Participants will be asked to provide demographics, descriptive characteristics of their ethics committee and their experiences of the ethics process. Participants will also be asked about the (a) importance of different types of Aboriginal and Torres Strait Islander engagement with research, and (b) how well they perceive researchers to engage Aboriginal and Torres Strait Islander communities in research (based on the key areas identified in [table 2](#)). There are currently 181 NHMRC-registered HRECs around Australia that will be invited to participate. A target sample of 100–500 participants is expected for the survey.

Interviews and yarning circles

At the end of the survey, participants will have the option to indicate their interest in participating in an interview or yarning circle (online or face to face). Recruitment will occur parallel to the survey data collection, including all interested participants to ensure all HREC members have the appropriate opportunity to be involved. We anticipate conducting yarning circles in two groups: (1) members from Aboriginal-specific ethics committees, (2) members from non-Aboriginal-specific committees. However, any participant may select one-on-one interviews if preferred. Twenty to 30 interviews or up to 10 yarning circles are expected to achieve adequate saturation of themes.

Interviews will be guided by an interview schedule and yarning guide and will take approximately 30–60 min. Questions will include perceptions of research practice and experiences related to the ethics approval process and perceived barriers or enablers for conducting ethical Aboriginal and Torres Strait Islander research. We will analyse the data in correspondence with ethical research guidelines and frameworks (see [table 2](#)).

Baarra 4: development of practical recommendations to support ethical research conduct

Baarra 4 will encompass a round table consisting of the Aboriginal and Torres Strait Islanders, participating communities, peak bodies and other Indigenous academics to develop a list of recommendations to support ethical research conduct. All ACCHOs (including CEOs, practice managers and staff) engaged in *baarra 1*, Aboriginal and Torres Strait Islander health researchers engaged in *baarra 2*, ethics committee members engaged in *baarra 3*, members of the NHLF and key stakeholders

identified through the ongoing consultation and engagement processes of the project will be invited to participate in the round table. The methods used to develop the recommendations will be developed in consultation during *baarra 1–3*.

Analysis of *baarra 1–3*

Quantitative data collected in the surveys will be summarised using counts and proportions. Logistic regressions will explore how characteristics of interest relate to survey outcomes. Interview and yarning circle data will be transcribed and analysed using NVivo V.12 software. Individual participants will have the option of receiving a written transcript of their responses prior to analysis and will be given the opportunity to edit their responses if they wish. Transcripts will be sent back to communities for approval before being included in the analysis. Two researchers (at least one Aboriginal) will independently code the qualitative data thematically using the developed Key Areas for Aboriginal and Torres Strait Islander Engagement in Health Research as a framework for analysis. Preliminary findings will be shared with the Aboriginal and Torres Strait Islander research team and NHLF for consideration. Once consensus of themes is reached by the research and advisory teams, feedback will be sought from all communities involved in the yarning circles. Data will be reported in line with community feedback to ensure voices are upheld with respect and integrity.

Ethics and dissemination

Ethics approvals

This project has received ethics approval from the AH&MRC HREC (reference no. 1924/22), AIATSIS HREC (reference no. EO323-20220414) and University of Newcastle HREC (reference no. H-2022-0211). The study will be conducted in accordance with the: NHMRC Road Map II: A Strategic Framework for Improving the Health of Aboriginal and Torres Strait Islander People through Research; Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research; and Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics.

Consent

Participation in the *Murru Minya* project is voluntary and participants may withdraw from the study at any time. The study information statements provide contact details for the research team to answer any questions. For all data collection activities, potential participants will be provided with a plain-language Participant Information Sheet and given time to consider their participation. Participants will be required to provide written informed consent for all data collection activities in *baarra 1–3*. For the surveys, participants will be required to answer the consent form at the beginning of the survey. For the interviews/yarning circles, participants will provide written consent, but with

the option of verbal consent if preferred (in line with the National Statement).

Confidentiality

Any planned or future use of data will present data only in de-identified and summary form and will adhere to strict security processes to ensure data privacy and confidentiality. The contact details asked at the end of the survey for interviews and yarning circles will not be linked with survey answers and will be deleted upon completion of data collection.

Dissemination

The project has been developed in line with principles of Indigenous data sovereignty, acknowledging the rights of Indigenous people to control the development and dissemination of data for and about them.⁴⁰ All reporting of findings for this research will be subject to multilevel approvals including the Aboriginal and Torres Strait Islander research team which includes leaders in Indigenous data sovereignty.

Murru Minya contracted an Indigenous media and marketing agency to create a website (www.murru-minya.com.au) that embodies what the *Murru Minya* project stands for, transparent ethical research. The website was designed to provide updates for the community on the project and its findings. Knowledge translation between the research team and community was at the forefront of the website's design, content and creation. Community members and the research team are featured in the images on the website, representing how *Murru Minya* will interact with communities around the country.

An integrated knowledge translation plan will be developed in partnership with the Lowitja Institute that will ensure ongoing feedback to communities and knowledge translation activities are meaningful and impactful for the project. The practical recommendations derived in this study will be published, open access, in a peer-reviewed national journal and online with Lowitja. Once published, this will be circulated through peak Aboriginal and Torres Strait Islander and research bodies. The recommendations will be made freely available to all interested parties to appropriately distribute.

Discussion and implications

This research builds on the priorities from the NHMRC Road Map 3, to 'improve the way all researchers work with Aboriginal and Torres Strait Islander people and communities; develop and/or strengthen research capabilities of communities, and enhance the rights of Aboriginal and Torres Strait Islander peoples as researchers, partners and collaborators in research'.⁴¹ Aboriginal and Torres Strait Islander communities have reported an overburden of research with little improvement to health outcomes experienced. Ethical guidelines outline the importance of research built on community priorities, reciprocal partnerships and benefit. Our team's previous research found community reports of researchers showing

insufficient regard for ethics processes for Aboriginal and Torres Strait Islander health research.¹³ The ways in which ethical guidelines are implemented are rarely reported in peer-reviewed literature; therefore, extensive national consultation is required to adequately address barriers and enablers in the uptake of ethical guidelines. Research quality and impact in Aboriginal and Torres Strait Islander health are aligned with ethical research conduct. Through privileging the voices and experiences of Aboriginal and Torres Strait Islander communities, this research has benefit to all those involved in Aboriginal and Torres Strait Islander health research including students, researchers, Aboriginal and Torres Strait Islander communities, peak bodies and funders. We acknowledge that Aboriginal and Torres Strait Islander peoples are diverse, and this study may not reflect the perspectives, experiences and recommendations of all peoples and communities. The research team includes both Aboriginal and Torres Strait Islander researchers located in all states and territories across the country with strong connections and working relationships with Aboriginal and Torres Strait Islander communities. The study design has carefully considered inclusive and culturally responsive research approaches to privilege diversity of our people and communities.

Baarra 1 will be the first national exploration of community experiences with Aboriginal and Torres Strait Islander health research implementation. It will generate new knowledge on the experiences of Aboriginal and Torres Strait Islander communities and help identify gaps in their engagement throughout the research process. *Baarra 2* will examine academic's perspective of research conduct in line with ethical guidelines, allowing key areas for refinement to be identified. The results of *baarra 2* will be further considered with the results of *baarra 1* to provide valuable information about how perceptions may differ between Aboriginal and Torres Strait Islander community experiences and researchers. These data will help identify barriers to ethical research implementation, developing new knowledge to strengthen research capabilities. *Baarra 3* will explore the perspective of HRECs to understand Aboriginal and Torres Strait Islander representation, administrative burden and processes for ethics applications. *Baarra 4* will comprehensively incorporate the findings from *baarra 1*, *2* and *3*, in line with current research literature and framework documents.

This project explores the implementation of ethical research for Aboriginal and Torres Strait Islander peoples (as presented in [tables 1 and 2](#)) in order to offer practical recommendations to refine research practice into the future. Students and academics will benefit from this comprehensive examination of ethical research implementation through data-based and community-informed practices relating to research design, implementation, and reporting for Aboriginal and Torres Strait Islander health research. Through these recommendations, more informed planning can occur, which will maximise efficiency in research implementation, increasing uptake of

ethical processes and the potential for positive research outcomes. Aboriginal and Torres Strait Islander communities and peak bodies are recognised as knowledge holders. Funding agencies across Australia can provide the practical recommendations to funded research teams to decrease potential delays in conducting Aboriginal and Torres Strait Islander research. Funding agencies will be offered Aboriginal and Torres Strait Islander community-informed processes, which will support the implementation of high-quality, ethical research. Aboriginal and Torres Strait Islander communities will benefit from a refined research process that addresses any reported barriers they face to engaging in meaningful research as co-owners and active participants.

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