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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

Romany McGuffog ,[1,2] Catherine Chamberlain,[3,4] Jaqui Hughes,[5] Kelvin Kong,[1,6] Mark Wenitong,[7] Jamie Bryant,[1,2] Alex Brown,[8,9] Sandra J Eades,[10] Kalinda E Griffiths,[11] Felicity Collis,[1,2] Breanne Hobden,[2,12] Peter O'Mara,[1] Tanika Ridgeway,[1] Maggie Walter,[13] Michelle Kennedy [1,2]

To cite: McGuffog R, Chamberlain C, Hughes J, *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**:e067054. doi:10.1136/bmjopen-2022-067054

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2022-067054).

Received 01 August 2022
Accepted 16 January 2023

For numbered affiliations see end of article.

Correspondence to
Dr Romany McGuffog; romany.mcguffog@newcastle.edu.au

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 reporting[28] 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.

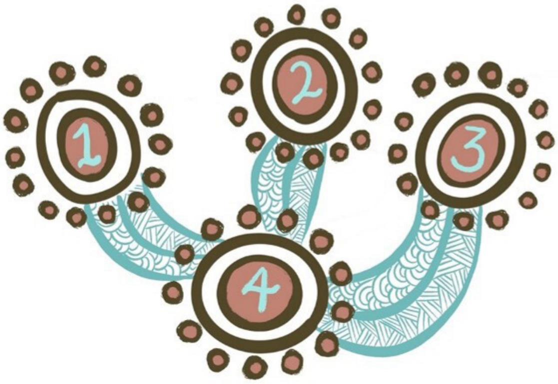

Figure 2 Overview of *baarra* (steps).

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 *winhanga-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]				**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]					
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	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	3	4	7	8
Adopt Indigenous data sovereignty and governance principles	1	3	5	6	1	4	7	1	2		2	3	4		1	2	4	6	7	8
Research agreements with Aboriginal communities	1	5	6		3			1	2		1	2	3	4	1	2	3	4	6	8
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		3	
Community engagement in research implementation	1	3	4	6	4			2			1	2	4		1	2		3	5	
Having Aboriginal project team members	1		6		4			2	5		1	2	4		1	2		3	6	
Community engagement in the analysis and interpretation of findings	1	2	3	6	5	6		2			1	2	4		1	2		3	7	
Reimbursement of costs	1							4							3			6		
Disseminating results to the community	1		6		7			5							1	2		7	9	
Involve community members as coauthors on publications and co-presenters on presentations	1	5	6		6			2	5		1	2	4		1	2		3	7	
Translating the results into action	1		6		7	8					1	2	3		1	2		6	9	

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 participated. 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.murruminya.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.

Author affiliations
[1]School of Medicine and Public Health, The University of Newcastle, Callaghan, New South Wales, Australia
[2]Hunter Medical Research Institute, The University of Newcastle, New Lambton, New South Wales, Australia
[3]Judith Lumley Centre, School of Nursery and Midwifery, La Trobe University, Melbourne, Victoria, Australia
[4]Centre for Health Equity, School of Population and Global Health, The University of Melbourne, Melbourne, Victoria, Australia
[5]Rural and Remote Health, College of Medicine and Public Health, Flinders University, Nhulunbuy, Northern Territory, Australia
[6]ENT Department, Hunter Valley Private Hospital, Newcastle, New South Wales, Australia
[7]Lowitja Institute, Carlton, Victoria, Australia
[8]Indigenous Genomics, Australian National University, Canberra, Australian Capital Territory, Australia
[9]Telethon Kids Institute, Nedlands, Western Australia, Australia
[10]Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, Melbourne, Victoria, Australia
[11]Centre for Big Data Research, University of New South Wales, Sydney, New South Wales, Australia
[12]Health Behaviour Research Collaborative, School of Medicine and Public Health, The University of Newcastle, Callaghan, New South Wales, Australia
[13]School of Social Sciences, University of Tasmania, Hobart, Tasmania, Australia

Twitter Romany McGuffog @RomanyMcGuffog

Acknowledgements We acknowledge that this research is conducted across unceded lands of Aboriginal and Torres Strait Islander peoples and pay respect to the elders and caretakers of the lands, seas, sky and waterways. We acknowledge that Aboriginal and Torres Strait Islander peoples are the knowledge holders and pay respect to their wisdom and processes for knowledge productions and knowledge sharing. We also wish to acknowledge the governing body for this project, the National Health Leadership Forum, and thank them for sharing their wisdom and expertise to ensure this research has tangible benefit and impact for our people.

Contributors MK conceived the study. MK, RM, FC and TR drafted the manuscript. MK, AB, JB, CC, SE, KG, BH, JH, KK, PO and MW are study investigators who contributed to the development of the project and study design. All authors provided comments and critical revisions on the manuscript and approved the final version.

Funding This project is funded by an NHMRC Ideas Grant (APP2001767) led by the University of Newcastle. This research was supported by funding from the HMRI Equity in Health and Wellbeing Research Program. This research was also supported by an Australian Government Research Training Program (RTP) Scholarship. BH is supported by a Colin Dodds Australian Rotary Health Postdoctoral Fellowship (G1801108). MK is funded by an NHMRC Early Career Fellowship #1158670. AB is supported by NHMRC Senior Research Fellowship (GNT1137563). JH is funded by NHMRC Emerging Leadership Fellowship (#1174758). KG is funded under the Scientia Program at the University of New South Wales (N/A).

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Author note To demonstrate the cultural positioning and Indigenous leadership of the research team, we have provided the traditional lands of our Aboriginal and Torres Strait Islander authors. We believe that providing this information is crucial to reflexive research and a critical part of being sovereign researchers. Catherine Chamberlain - Palawa Trawlwoolway; Jaqui Hughes - Wagadagam; Kelvin Kong - Worimi; Mark Wenitong - Kabi Kabi; Alex Brown - Yuin; Sandra Eades - Noongar; Kalinda Griffiths - Yawuru; Felicitiy Collis - Gomeroi; Peter O'Mara - Wiradjuri; Tanika Ridgeway - Worimi; Maggie Walter - Palawa; Michelle Kennedy - Wiradjuri

ORCID iDs
Romany McGuffog http://orcid.org/0000-0001-6071-6199
Michelle Kennedy http://orcid.org/0000-0001-9691-068X

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Murru
Minya

BAARRA 1

Community

Baarra 1 – Survey for Community

Prefer to yarn through these questions? Murru Minya have Aboriginal and Torres Strait Islander staff happy to complete this with you. Give us a call on (02) 4921 7757.

Demographics

1. What best describes your service?
    - Aboriginal Community Controlled Health Service
    - Aboriginal Health service (not community controlled)
    - Local Aboriginal Land Council
    - Other (please specify)

2. What is the postcode of your service?
    - [Open-ended]

3. In general, how do you feel about research?
    - Very negative
    - Slightly negative
    - Neutral
    - Slightly positive
    - Very positive

4. Does your service have any formal processes for research approval and/or governance?
    - Yes
    - No

5. [If select No in Q4] Do you have an interest in building formal processes for research approval and/or governance?
    - Yes
    - No

6. Over the last five years, approximately how many times has your service been **approached** to participate in research?
    - [Sliding scales in from 0-20+]

7. OPTIONAL: Feel free to provide additional details about being approached to participate in research. These can be dot points.
    - [Open-ended]

8. Over the last five years, approximately how many times have you **agreed to participate** in research?
    - [Sliding scales in from 0-20+]

9. OPTIONAL: Feel free to provide additional details about why you agreed to participate in certain research projects. These can be dot points.
    - [Open-ended]

10. Over the last five years, approximately how many times have you **withdrawn from a project** that you originally agreed to participate in?

- [Sliding scales in from 0-20+]

11. OPTIONAL: Feel free to provide additional details about why you withdrew from certain research projects. These can be dot points.
    - [Open-ended]

12. Have you participated in any research that was Indigenous-led?
    - Yes
    - No
    - Don’t know

13. [If select Yes in Q13] OPTIONAL: Please describe any unique features about your experiences with this type of research. These can be dot points.
    - [Open-ended]

14. In general, has research been a benefit for your community?
    - Not at all
    - Sometimes
    - Often
    - Always
    - Don’t know

Aboriginal Engagement in Research
There are a number of ethical guidelines (e.g., NHMRC Ethical Conduct, Keeping Research on Track, AIATSIS Code of Ethics, and AH&MRC Ethical Guidelines) that outline the importance of involvement of Aboriginal and Torres Strait Islander people in the conduct of Aboriginal and Torres Strait Islander health research. For each area, please tell us **how important you think this area is for Aboriginal health research**.

	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
15. Community identifies the research priorities						
16. Community developing the research questions						
17. Research has community governance, advisory and decision making on the project						
18. Researchers enact Indigenous data sovereignty and governance principles						

19. Research agreements are developed between communities and researchers						
20. Research embeds opportunities for capacity building of communities						
21. Research embeds opportunities for capacity building of the research team (I.e., developing cultural capabilities)						
22. Community implements the research						
23. Research employs Aboriginal and Torres Strait Islander staff						
24. Community oversight in analysing/interpreting the findings						
25. Reimbursement of costs to communities for partnership and involvement						
26. Community receive payment for sitting fees (i.e., for research meetings)						
27. Researchers share the results of the research back to communities						
28. Community members are co-authors on publications and co-presenters on presentations						
29. Researchers translate the findings into policy and/or practice						

30. What are the reasons your service has or would participate in research?
    - [Open-ended]

31. What are the reasons your service would not, or has not participated in research?
    - [Open-ended]

32. Do you think there is anything needed to improve the conduct of Aboriginal and Torres Strait Islander research? (E.g., particular training, resources, etc.)
    - [Open-ended]

33. Do you have any additional comments about your experiences in research?
    - [Open-ended text]

End of Survey

To thank you for your time, we will have 5 x $100 vouchers your community can use as you see fit. To go in the draw for this, please provide your best contact details. This information will be kept separate from your survey responses so that your responses cannot be identified.

Contact information (i.e., email, phone number): ______________________________________

The Murru Minya project will be travelling across the country to yarn with Aboriginal and Torres Strait Islander communities (i.e., the board, staff members, and community members) about research to understand experiences of research, and what communities feel is needed to improve research into the future.

If you are interested in nominating your service to participate in a yarning circle, please indicate below and we will make contact with you and share more information on this. This information will be kept separate from your survey responses so that your responses cannot be identified.

- Yes, I am interested in nominating my service in a yarning circle (please indicate best form of contact)
- No, I am not interested

More details on the Murru Minya project can be found on our website: www.murruminya.com.au

[Add some linked icons for the website, mailing list, etc.]

Baarra 1 Community Yarning Circles V1_14.02.2022

Baarra 1 – Yarning Circle for Community

Objectives:

To identify, through the voices and experiences of Aboriginal and Torres Strait Islander communities their experiences and perceptions of:

- The way health research has been conducted in their community,
- Barriers and enablers to participating in Aboriginal and Torres Strait Islander health research, and
- Communities report of researchers' adherence to ethical principles.

***This interview process will follow yarning method (Bessarab 2010) which includes a participant led approach. As such we will use domains of enquiry rather than semi-structured interview questions. We have included example questions.*

Opening:

The yarning circle will open with social yarning to build rapport and establish social and cultural positioning of the researchers. The yarning circle will be conducted by Aboriginal and/or Torres Strait Islander research team members in partnership with local service nominated representative.

Consent:

The Aboriginal and/or Torres Strait Islander research team member will then begin research topic yarning which will explain the detail in the Participant information sheet (which all participants will have a copy of, provided when they entered the room). Participants will have the opportunity to have any questions answered and be reminded that the project is voluntary and they can change their mind at any time and exit the room/space. All consent will be obtained at this point on hard copy or digital files (ie. Signed on an ipad).

Collaborative yarning:

The Aboriginal and/or Torres Strait Islander research team member will then begin the collaborative yarning which will be recorded. Participants will also be offered ipads and pencils to allow drawing and visual reflections on the discussions to be documented.

Domains of enquiry:

1. Community's experiences of participating in research
2. What community's feel is needed to improve the conduct of health research

Can you tell me about your community's experiences of health research?

Prompts:

Baarra 1 Community Yarning Circles V1_14.02.2022

- Can you tell me about your communities experiences being involved in health research?
- Can you tell me about your communities relationships with researchers in developing research?
- Can you tell me about aspect of health research in this community that may not have been positive?
- Can you tell me about how researchers could/ or should work with your community?
- Can you tell me about any processes your community have to participate/oversee research?
- Can you tell me about any Indigenous led projects you have been involved in, how these might be different to other projects not led by Indigenous researchers?
- Can you tell me any processes your community has to ensure your research priorities are addressed in research?

What do you feel is needed to improve the conduct of health research?

- Can you tell me how researchers could do better?
- Can you tell me what you would like in the future to ensure research is of benefit to your community?

Murru
Minya

BAARRA 2
Researchers

Baarra 2 – Survey for Researchers

Demographics

1. What is your age in years?
    - Under 25 years
    - 25-34 years
    - 35-44 years
    - 45-54 years
    - 55-64 years
    - 65-74 years
    - Over 75 years

2. What is your gender?
    - Woman or female
    - Man or male
    - Nonbinary
    - I use a different term (please specify)
    - Prefer not to say

3. Are you Aboriginal or Torres Strait Islander?
    - Yes, Aboriginal
    - Yes, Torres Strait Islander
    - Yes, Aboriginal and Torres Strait Islander
    - No

4. Do you identify with another Indigenous population?
    - Yes (please specify)
    - No

5. What best describes your role/position?
    - Current graduate student studying a higher research degree (Masters or PhD)
    - Early career, ≤5 years since PhD completion
    - Mid-career >5 but <10 years since PhD completion
    - Senior career >10 years since PhD completion
    - Non-academic role (e.g., Research Assistant, Project Manager, Clinical profession)
    - Research Assistant/Project Manager
    - Clinical position
    - Research consultant
    - Other (please specify)

6. How many years (to the nearest whole year) have you been undertaking research in the area of Aboriginal and Torres Strait Islander health?
    - [Sliding scales in years from 0-50+]

7. Which organisation is your primary place of employment for undertaking research? Tick all that apply.
    - University
    - Hospital

  - Research Institute
  - Government agency
  - Aboriginal community-based organisation (I.e., health service, land council)
  - Mainstream primary care setting
  - Non-government organisation (NGO)
  - Private sector
  - Other (please specify)

8. In which state or territory is this organisation located?
    - New South Wales
    - Victoria
    - Queensland
    - Northern Territory
    - Western Australia
    - South Australia
    - Tasmania
    - Australian Capital Territory
    - Outside of Australia (please specify)

9. Which state or territory have you conducted Aboriginal and Torres Strait Islander research in? Tick all that apply.
    - New South Wales
    - Victoria
    - Queensland
    - Northern Territory
    - Western Australia
    - South Australia
    - Tasmania
    - Australian Capital Territory
    - National

10. Do you usually conduct research in partnership with the Aboriginal and/or Torres Strait Islander community where you are based?
    - Never
    - Sometimes
    - Often
    - Always

11. Do you usually partner with any Aboriginal Controlled Community Health Organisations (ACCHO) for any of your research?
    - Never
    - Sometimes
    - Often
    - Always

12. What area of Aboriginal and Torres Strait Islander research does your research primarily focus on? Please list your top 3.
    - [Open-ended]

13. Currently, what proportion of your research time is dedicated to Aboriginal and Torres Strait Islander specific research? Please select your answer as a percentage of your ***research*** time.
    - Less than 25%
    - Approximately 25% to 50%
    - Approximately 50% to 75%
    - Approximately 75% to 100%

14. Over your career, has your time committed to Aboriginal-specific research changed?
    - Increased
    - About the same
    - Decreased
    - Other (please describe)

The Ethics Process

The next set of questions are about ethics processes in your research. Please consider your responses to these questions in relation to the **last five years**.

15. At what stage do you usually first consult with Aboriginal and Torres Strait Islander communities?
    - Idea generation and conception
    - During the funding application process
    - Once funding has been allocated but before beginning the ethics application process
    - During the ethics application process
    - After receiving ethics approval
    - I don’t consult Aboriginal and Torres Strait Islander communities

16. What ethical guidelines do you commonly use to guide your Aboriginal and Torres Strait Islander health research? Tick all that apply.
    - NHMRC Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders
    - AH&MRC Guidelines for Ethical Research in Aboriginal communities
    - AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research
    - Other (please specify)

17. For any of the Aboriginal and Torres Strait Islander health research you have conducted, were multi-state ethics approvals required?
    - Never
    - Sometimes
    - Often
    - Always

18. For any of the Aboriginal and Torres Strait Islander health research you have conducted, did you seek approval from an Aboriginal-specific ethics committee?
    - Yes (e.g., AH&MRC, WAAHEC)
    - No, but other community-based committees (e.g., Waminda)
    - No (please detail why)

19. What is the maximum number of Aboriginal-specific ethics committees that you have applied to for a single project?
    - [Open-ended]

20. Have you participated in any form of ethics training specifically for Aboriginal and Torres Strait Islander research?
    - Yes (i.e., institutional training) (please specify)
    - No

21. How confident do you feel managing the ethics application process for your Aboriginal and Torres Strait Islander health projects?
    - Not at all confident
    - Somewhat confident
    - Fairly confident
    - Very confident
    - Extremely confident

22. Do you have any reflections on the ethics process?
    - [Open-ended]

Aboriginal and Torres Strait Islander Engagement in Research
There are a number of ethical guidelines (e.g., NHMRC Ethical Conduct, Keeping Research on Track, AIATSIS Code of Ethics, and AH&MRC Ethical Guidelines) that outline the importance of involvement of Aboriginal and Torres Strait Islander people in the conduct of Aboriginal and Torres Strait Islander health research. For each area, please tell us **how important you think this area is for Aboriginal health research**.

	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
24. Aboriginal community identifying research priorities						
25. Aboriginal community developing the research questions						
26. Aboriginal governance, advisory and decision making on the project						
27. Enacting Indigenous data sovereignty and governance principles						

28. Research agreements with Aboriginal communities						
29. Embedding opportunities in the research for capacity building for Aboriginal communities						
30. Embedding opportunities in the research for capacity building of the research team for research with Aboriginal communities (I.e., developing cultural capabilities)						
31. Aboriginal community implementing research						
32. Employing Aboriginal project team members						
33. Aboriginal community oversight in analysing/interpreting the findings						
34. Aboriginal community are reimbursed for the costs for partnership and involvement						
35. Aboriginal community receive payment for sitting fees (i.e., for research meetings)						
36. Researchers disseminate results back to Aboriginal communities						
37. Aboriginal community members as co-authors on publications and co-presenters on presentations						
38. Researchers translate the findings into policy and/or practice						

Think about the **most recent completed project in Aboriginal and Torres Strait Islander health** that you were involved in. If you have not been part of a completed project, think about a project closest to completion and for sections that do not apply, select N/A.

39. What is the research design? (E.g., intervention, qualitative, etc.)
    - [Open-ended]

40. What state or territory was the project conducted in? Please tick all that apply.
    - New South Wales
    - Victoria
    - Queensland
    - Northern Territory
    - Western Australia
    - South Australia
    - Tasmania
    - Australian Capital Territory
    - National
    - Outside of Australia (please specify)

41. How much funding was received for the project:
    - $0 to $100,000
    - $100,000 to $500,000
    - $500,000 to $1,000,000
    - More than $1,000,000

For this project, **how well did you**:

	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	N/A (9)
42. Engage Aboriginal community in identifying research priorities						
43. Engage Aboriginal community in developing the research questions						
44. Embed Aboriginal governance, advisory and decision making on the project						
45. Enact Indigenous data sovereignty and governance principles						
46. Develop Research agreements with Aboriginal communities						

47. Embed opportunities in the research for capacity building for Aboriginal communities						
48. Embed opportunities in the research for capacity building of the research team for research with Aboriginal communities (I.e., developing cultural capabilities)						
49. Engage Aboriginal community in research implementation						
50. Employ Aboriginal project team members						
51. Engage Aboriginal community in the analysis and interpretation of findings						
52. Reimburse costs to communities for partnership and involvement						
53. Pay community members for sitting fees (i.e., for research meetings)						
54. Disseminate results back to the community						
55. Involve community members as co-authors on publications and co-presenters on presentations						
56. Translate the findings into policy and/or practice						

This next question isn't about a particular researcher or team. We would like you to reflect on Aboriginal and Torres Strait Islander research as a whole. **How well you think researchers working in Aboriginal health:**

	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
57. Engage Aboriginal community in identifying research priorities						
58. Engage Aboriginal community in developing the research questions						
59. Embed Aboriginal governance, advisory and decision making on the project						
60. Enact Indigenous data sovereignty and governance principles						
61. Develop Research agreements with Aboriginal communities						
62. Embed opportunities in the research for capacity building for Aboriginal communities						
63. Embed opportunities in the research for capacity building of the research team for research with Aboriginal communities (I.e., developing cultural capabilities)						
64. Engage Aboriginal community in research implementation						
65. Employ Aboriginal project team members						
66. Engage Aboriginal community in the analysis and interpretation of findings						
67. Reimburse costs to communities for						

partnership and involvement						
68. Pay for community for sitting fees (i.e., for research meetings)						
69. Disseminate results back to the community						
70. Involve community members as co-authors on publications and co-presenters on presentations						
71. Translate the findings into policy and/or practice						

Barriers and Enablers in Aboriginal and Torres Strait Islander Research

As part of our research, we have reviewed literature in Aboriginal and Torres Strait Islander health for the barriers and enablers identified by researchers. The following questions use these barriers and enablers.

72. In your experience, what do you feel are the **top three enablers** for conducting Aboriginal and Torres Strait Islander health research?
    - Community interaction (e.g., community-developed, co-design, community involvement and partnerships)
    - Community governance
    - Community data ownership
    - Indigenous project members
    - Indigenous-led and/or Indigenous leadership
    - Sample characteristics (e.g., good sample sizes, generalisability, representativeness, low attrition)
    - Being culturally appropriate/safe for participants, communities, etc.
    - Capacity building for the research team
    - Capacity building for the community
    - Providing resources or reducing costs to community
    - Understanding local culture and context
    - Incorporating Indigenous methods/methodologies
    - Having an appropriate/flexible time frame
    - Other (please specify)

73. In your experience, what are the **top three barriers** for conducting Aboriginal health research?
    - Difficulties obtaining sample size (e.g., low sample size, attrition, missing data, staff turnover)

  - Difficulties with generalisability of findings (e.g., lack of representativeness, low power, low data quality)
  - Issues related to funding, costs, and/or resources
  - Impact of time (e.g., timeframe was too short or too long)
  - Capacity of community and/or people involved
  - Lack of community involvement
  - Communication issues
  - Other (please specify)

74. Do you think there is anything needed to improve the conduct of Aboriginal and Torres Strait Islander research? (E.g., particular training, resources, etc.)
    - [Open-ended]

75. Do you have any final comments about conducting research with Aboriginal and Torres Strait Islander communities?
    - [Open-ended]

End of Survey

The Murru Minya project will be conducted one on one interviews with researchers/research teams to better understand the barriers and enablers experienced by researchers when conducting Aboriginal and Torres Strait Islander health research in line with ethical guidelines.

If you are interested in participating in these interviews, please indicate below and we will make contact with you and share more information on this:

  - Yes, I am interested in participating in an interview (please provide your best form of contact)
  - No, I am not interested

[Linked icons for the website, mailing list, etc.]

Baarra 2 – Interview Schedule for Researchers

Demographic Survey [To be completed by interviewer at the beginning of the interview]:

1. What is your age in years?
    - Under 25 years
    - 25-34 years
    - 35-44 years
    - 45-54 years
    - 55-64 years
    - 65-74 years
    - Over 75 years

2. What is your gender?
    - Woman or female
    - Man or male
    - Nonbinary
    - I use a different term (please specify)
    - Prefer not to say

3. Are you Aboriginal or Torres Strait Islander?
    - Yes, Aboriginal
    - Yes, Torres Strait Islander
    - Yes, Aboriginal and Torres Strait Islander
    - No

4. Do you identify with another Indigenous population?
    - Yes (please specify)
    - No

5. Which state or territory are you located?
    - New South Wales
    - Victoria
    - Queensland
    - Northern Territory
    - Western Australia
    - South Australia
    - Tasmania
    - Australian Capital Territory
    - Prefer not to say

Domains of enquiry

***This interview process will follow yarning method (Bessarab 2010) which includes a participant led approach. As such, we will use domains of enquiry rather than semi-structured interview questions. We have included example questions.*

Barriers and enablers to conducting Aboriginal health research

Q: Can you tell me about your experiences of conducting research in Aboriginal and Torres Strait Islander health?

Baarra 2 Researchers Interview Schedule V1_14.02.2022

Q: Can you tell me a bit about the type of Aboriginal and Torres Strait Islander health research you conduct and any barriers or challenges you have?

Q: Can you tell me about the things you feel are needed to do Aboriginal and Torres Strait Islander health research well?

Q: Can you tell me a bit about the ethics approval processes you normally undertake? Are there any particular barriers or enablers to this process?

Adherence to ethical principles

Q: Can you share some insight to how you apply ethical research principles in your Aboriginal and Torres Strait Islander health research?

Q: Can you share some insight to your approach when working with Aboriginal and Torres Strait Islander communities?

Q: Can you share some of the challenges to you have experienced in engaging community in your research?

Q: Can you tell me about how manageable the ethics processes are for your type of research?

Q: Can you share some of the challenges you have experienced in obtaining ethics approval for your projects?

Q: Can you tell me about how you embed opportunities in your research for capacity building?

Q: Can you tell me about how you reimburse costs to Aboriginal and Torres Strait Islander communities/participants in your research?

Q: Can you tell me about some of the ways you have disseminated results back to the community and beyond?

Q: Do you have any suggestions for how researchers can better conduct research with Aboriginal and Torres Strait Islander communities?

BAARRA 3

Human Ethics Research Committees

Baarra 3 – Survey for HRECs

Prefer to yarn through these questions? Murru Minya have Aboriginal and Torres Strait Islander staff happy to complete this with you. Give us a call on (02) 4921 7757.

Screening

1. Are you currently a member of an ethics committee?
    - Yes
    - No (but was a member within the last five years)
    - No (but was a member more than five years ago) [End of survey]
    - Never been a member [End of survey]

2. Does your committee receive applications related to Aboriginal and Torres Strait Islander research?
    - Yes
    - No [End of survey]

Demographics

3. What is your age in years?
    - Under 25 years
    - 25-34 years
    - 35-44 years
    - 45-54 years
    - 55-64 years
    - 65-74 years
    - Over 75 years

4. What is your gender?
    - Woman or female
    - Man or male
    - Nonbinary
    - I use a different term (please specify)
    - Prefer not to say

5. Are you Aboriginal or Torres Strait Islander?
    a. Yes, Aboriginal
    b. Yes, Torres Strait Islander
    c. Yes, Aboriginal and Torres Strait Islander
    d. No

6. Do you identify with another Indigenous population?
    - Yes (please specify)
    - No

7. How are you remunerated for your time on the ethics committee?
    - None (part of academic service, etc.)

- None (volunteer)
- Financially
- Non-financial (honorary position, library access etc)
- Other (please specify)

8. Which state or territory is your ethics committee located?
    - New South Wales
    - Victoria
    - Queensland
    - Northern Territory
    - Western Australia
    - South Australia
    - Tasmania
    - Australian Capital Territory
    - Prefer not to say

9. Which best describes the ethics committee you are/have been a part of:
    - Institutional committee (e.g., University, Research Institute)
    - Health service committee (e.g., Local Health District, hospitals, health centres)
    - Aboriginal-specific committee
    - Aboriginal-specific sub-committee
    - Other (please specify)
    - Prefer not to say

10. [If select any option other than Aboriginal-specific committee or Aboriginal sub-committee in previous question] Does your ethics committee require approval from and Aboriginal-specific committee/sub-committee?
    - Yes (before application is reviewed)
    - Yes (after application is reviewed)
    - No
    - Don't know

11. [If select any option other than Aboriginal-specific committee or Aboriginal sub-committee in previous question] Does the ethics committee you are/have been part of ratify Aboriginal-specific ethics approvals?
    - Yes
    - No
    - Don't know

12. [If select any option other than Aboriginal-specific committee or Aboriginal sub-committee in previous question] Does the ethics committee you are/have been part of currently have an Aboriginal and/or Torres Strait Islander representative position?
    - Yes
    - No
    - Don't know

13. [If select yes to previous question] Is this position currently filled?
    - Yes

- No
- Don't know

14. Does the ethics committee you are/have been part of require Aboriginal-specific review/approval for research on the general population where Aboriginal and Torres Strait Islander people are likely to be part of the sample?
    - Never
    - Sometimes
    - Often
    - Always
    - Don't know

15. How confident are you reviewing Aboriginal-specific ethics applications?
    - Not at all confident
    - Somewhat confident
    - Fairly confident
    - Very confident
    - Extremely confident

16. Does the ethics committee you are/have been part of provide any training in Aboriginal and Torres Strait Islander research **for ethics committee members**?
    - Yes
    - No

17. Does the ethics committee you are/have been part of provide any training in Aboriginal and Torres Strait Islander research **for researchers**?
    - Yes
    - No

18. [If select no to previous question] Is there any training that your committee recommends?
    - Yes (please specify)
    - No

The Ethics Process

19. On average, how many ethics applications does the ethics committee you are/have been part of receive for Aboriginal-specific research over a 12-month period?
    - [Sliding scale from 1-100+]

20. How manageable is the **quantity** of ethics applications for Aboriginal-specific research that are submitted to the ethics committee you are/have been part of?
    - Not at all manageable
    - Somewhat manageable
    - Fairly manageable
    - Mostly manageable
    - Completely manageable

21. What level of **quality** are initial applications for Aboriginal-specific research that are submitted to the ethics committee you are/have been part of (I.e., well-prepared and in-line with your guidelines)?
    - Very poor
    - Poor
    - Fair
    - Good
    - Very good

22. What is the most common initial outcome on the ethics committee you are/have been part of for ethics applications for Aboriginal and Torres Strait Islander research?
    - Approved first time with no amendments
    - Approved but with minor amendments
    - Major amendments required
    - Rejected

23. In general, how many times do you go back and forth with researchers to address issues/amendments for their ethics applications in Aboriginal and Torres Strait Islander research?
    - [Sliding scale from 0-10+]

24. In your experience, what areas of ethics applications do researchers most often require additional assistance/amendments before receiving approval? Tick all that apply.
    - Research design
    - Appropriate research team members
    - Appropriate consultation with Aboriginal and Torres Strait Islander community
    - Appropriate partnerships with Aboriginal and Torres Strait Islander community
    - Appropriate recruitment processes
    - Appropriate consent processes
    - Appropriate Aboriginal and Torres Strait Islander Governance of the research
    - Culturally sensitive practices
    - Potential identifying information
    - Having appropriate Funding
    - Having appropriate Information Statements consent forms
    - Appropriate Cultural advisory
    - Addressing Aboriginal and Torres Strait Islander ethical values/principles in application
    - Data storage and access
    - Planned activities for the data
    - Risks and burdens associated with research (too high)
    - Risks and burdens associated with research not addressed/mitigated
    - Benefit of the research for Aboriginal and Torres Strait Islander community
    - Dissemination of findings to community
    - Dissemination of findings to participants
    - Other (please specify)

25. Do you have any further comments about the ethics process at the ethics committee you are/have been part of for ethics applications for Aboriginal and Torres Strait Islander research? [Open-ended]

Aboriginal Engagement in Research

There are a number of ethical guidelines (e.g., NHMRC Ethical Conduct, Keeping Research on Track, AIATSIS Code of Ethics, and AH&MRC Ethical Guidelines) that outline the importance of involvement of Aboriginal and Torres Strait Islander people in the conduct of Aboriginal and Torres Strait Islander research. In your experience of ethics applications, please tell us:

a. **How important you think this area is for Aboriginal and Torres Strait Islander research?**
b. **How well you think researchers in their ethics applications with engage Aboriginal and Torres Strait Islander people in each area?**

22. Community identifying research priorities						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
23. Community developing the research questions						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
24. Embedding community governance, advisory and decision making on the project						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
25. Enacting Indigenous data sovereignty and governance principles						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
26. Developing research agreements with communities						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)

27. Embedding opportunities in the research for capacity building for communities						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
28. Embedding opportunities in the research for capacity building of the research team for research with communities (I.e., developing cultural capabilities)						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
29. Community implementing the research						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
30. Employing Aboriginal and Torres Strait Islander project team members						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
31. Community oversight in analysing/interpreting the findings						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
32. Reimbursement of costs to communities for partnership and involvement						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
33. Payment to community for sitting fees (i.e., for research meetings)						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)

34. Researchers disseminating results back to the community						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
35. Community members as co-authors on publications and co-presenters on presentations						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)
36. Researchers translate the findings into policy and/or practice						
a. How **important** is this?	Not at all (1)	A little (2)	Moderate (3)	Very (4)	Essential (5)	I am unaware (9)
b. How **well do researchers** do?	Poor (1)	Fair (2)	Good (3)	Very Good (4)	Excellent (5)	I am unaware (9)

37. Do you think there is anything needed to improve/refine the **ethics processes** for Aboriginal and Torres Strait Islander research? (E.g., particular training, resources, etc.)
    a. [Open-ended]

38. Do you have any additional comments?

End of Survey
The Murru Minya project will be conducting online and face to face interviews with members of ethics committee to better understand how research is being conducted in Aboriginal and Torres Strait Islander health and what is needed to improve the uptake and adherence to ethical guidelines into the future.

If you are interested in participating in an interview, please indicate below and we will make contact with you and share more information on this:

- Yes, I am interested in participating in an interview (please provide your best form of contact)
- No, I am not interested

[Linked icons for the website, mailing list, etc.]

Baarra 3 – Interview Schedule for HRECs

Demographics (sent to participants via RedCap link to capture):

1. What is your age in years?
    - Under 25 years
    - 25-34 years
    - 35-44 years
    - 45-54 years
    - 55-64 years
    - 65-74 years
    - Over 75 years

2. What is your gender?
    - Woman or female
    - Man or male
    - Nonbinary
    - I use a different term (please specify)
    - Prefer not to say

3. Are you Aboriginal or Torres Strait Islander?
    - Yes, Aboriginal
    - Yes, Torres Strait Islander
    - Yes, Aboriginal and Torres Strait Islander
    - No

4. Do you identify with another Indigenous population?
    - Yes (please specify)
    - No

5. Are you currently a member of an ethics committee?
    - Yes
    - No (but was a member within the last five years)
    - No (but was a member more than five years ago)

6. Which state or territory is your ethics committee located?
    - New South Wales
    - Victoria
    - Queensland
    - Northern Territory
    - Western Australia
    - South Australia
    - Tasmania
    - Australian Capital Territory
    - Prefer not to say

7. Describe your ethics committee:
    - Institutional committee (e.g., University, Research Institute)
    - Health service committee (e.g., Local Health District, hospitals, health centres)
    - Aboriginal-specific committee
    - Aboriginal-specific sub-committee
    - Other (please specify)

- Prefer not to say

Domains of enquiry
***This interview process will follow yarning method (Bessarab 2010) which includes a participant led approach. As such we will use domains of enquiry rather than semi-structured interview questions. We have included example questions.*

1. **HRE Committee structures ie. Aboriginal reps, roles, size, renumerations etc.**

   Q. Can you tell me about how your committees are structured?

   Q. Are there any benefits to these current structures?

   Q. Are there any challenges to these current structures?

   Q. Can you suggest a ‘best practice’ model for structuring an ethics committee to review/approve Aboriginal and Torres Strait Islander health research?

   Q. Do you feel there is something lacking in current ethics committee structures for reviewing/approving Aboriginal and Torres Strait Islander health research?

2. **Challenges with current ethics review/approval processes**

   Q. Can you tell me about the processes your committee uses when reviewing/approving research relating to Aboriginal and Torres Strait Islander health?

   Q. Are there any challenges you or your committee face within these current processes?

   Q. Can you tell me about how manageable you find the current processes?

3. **What is needed to improve conduct of research/ researchers practice**

   Q. What do you feel could be in place to improve the conduct of Aboriginal and Torres Strait Islander health research?

   Q. What do you feel could be in place to improve the ethics process for researchers and Aboriginal and Torres Strait Islander communities.