Aboriginal and Torres Strait Islander community experiences and recommendations for health and medical research: a mixed methods study

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The known: Aboriginal and Torres Strait Islander communities have been at the forefront of advocating for improved health and medical research for the past four decades.

The new: Communities continue to have negative experiences of research despite ethical guidelines being developed to guide researchers and institutions. While most communities reported having formal governance processes for research, almost half reported that research is sometimes or never of benefit.

The implications: Urgent attention is required for researchers, funding bodies and institutions to invest in Aboriginal and Torres Strait Islander communities to lead, control and govern their own research.

Abstract

Objective: To describe Aboriginal and Torres Strait Islander communities' processes, positioning and experiences of health and medical research and their recommendations.

Design: A cross-sectional online and paper-based survey.

Setting, participants: Representatives from Aboriginal and Torres Strait Islander health services and community-controlled organisations in Australia.

Main outcome measures: Responses to a 33-item mixed methods survey that explored communities' positioning and processes relating to health and medical research and their experiences of health and medical research in the previous 5 years. Recommendations for improving health and medical research were elicited via two open-ended questions.

Results: Fifty-one community representatives nationally responded to the survey. Most representatives reported feeling slightly or very positive about research (37, 73%). More than half (33, 65%) reported having formal governance processes, and two-thirds of those without governance processes were interested in establishing such processes (12, 67%). Almost half reported that research has sometimes or never had benefit (25, 49%). Ethical principles that were most often reported as essential included those relating to sharing results back with community (45, 88%), translating research into policy and practice (37, 73%), employing Aboriginal and Torres Strait Islander staff (37, 73%), Indigenous data sovereignty and governance (36, 71%) and research agreements (35, 69%). Community representatives reported being approached frequently and in the later stages of research, with little input during the development and design stages of research. Most representatives reported that their communities had participated in Indigenous-led research (39, 76%). Community representatives highlighted the need for appropriate resourcing and funding to drive and lead their own research agendas.

Conclusion: Aboriginal and Torres Strait Islander communities continue to have negative experiences of research despite four decades of advocating for control, ownership and leadership of health and medical research. Researchers, funding bodies and institutions must examine current funding and research structures that reinforce current practices, to ensure transparency and accountability to communities by repositioning and giving power to communities to direct and lead their own health and medical research agendas.

Since 1982, Aboriginal and Torres Strait Islander communities have been at the forefront of driving and advocating for ethical research practices that centre their rights to ownership, control and governance of health and medical research that involves them.[1] The Australian Department of Health and Aged Care specifies that "Research establishes an evidence base to inform our policies, programs and services and ensure they are improving the health of Aboriginal and Torres Strait Islander people as intended" and that "This is a key part of the health system being accountable to Aboriginal and Torres Strait Islander people".[2] The National Health and Medical Research Council (NHMRC) stipulates that all research with Aboriginal and Torres Strait Islander communities, whether directly or indirectly, should be "safe, respectful, responsible, high quality, of benefit to Aboriginal and Torres Strait Islander people and communities" and should be used to enhance their rights.[3] Underpinning this are the fundamental rights of Aboriginal and Torres Strait Islander people to be involved in leadership and decision making throughout all stages of research that affects them.[4-6]

Nearly five decades on from the establishment of ethical guidelines, principles and practices for health and medical research focused on Aboriginal and Torres Strait Islander peoples and communities, there have been no national investigations of communities' experiences of research. Further, their processes and the positions they adopt, in relation to health and medical research, have not been explored. A recent community-led report from 15 years of research conducted with Aboriginal and Torres Strait Islander peoples in the Kimberley highlighted a lack of transparency, involvement, genuine partnership, control and direct impact of research, despite the existence of ethical guidelines promoting otherwise.[7] It is critical that the voices and experiences of communities are reported to ensure ethical guidelines are appropriately upheld and remain relevant in the ever-changing landscape of Aboriginal and Torres Strait Islander health and medical research.

Murru Minya is a national study examining the implementation of ethical research practices and processes in Aboriginal and

Torres Strait Islander health. In this study, we aimed to describe Aboriginal and Torres Strait Islander communities' involvement in health research, specifically regarding their:

- processes and positioning relating to health and medical research;
- experiences of health and medical research in the previous 5 years; and
- recommendations of how to improve health and medical research.

Methods

Research team

The concept of ethical practice is not new to Aboriginal and Torres Strait Islander peoples. Our ways of being incorporate a praxis of ethics that connects to our relational world view.[8] We acknowledge that the ways in which this research was conducted are deeply rooted in our lived experience and relationality. Consequently, this intrinsically influences how Aboriginal and Torres Strait Islander people have engaged in the *Murru Minya* study. This work was conducted in line with Indigenist methodology described by Lester-Irabinna Rigney and aims "to delegitimate racist oppression in research and shift to a more empowering and self-determining outcome"[9] through an exploration of the ways in which research is conducted, as examined by a collective of Aboriginal and Torres Strait Islander researchers.

The *Murru Minya* project was conceptualised by MK (Wiradjuri woman), in partnership with other Aboriginal (AB, MW, SJE, CC, KMK, PO, FC, and KEG) and Torres Strait Islander (JH) researchers located across these ancestral lands and geographies. This study was supported by the non-Indigenous supervisors (JB, KB) of Aboriginal PhD candidate FC.

This work is grounded in our standpoint which, as described by Martin Nakata "is a distinct form of analysis, and is itself both a discursive construction and an intellectual device to persuade others and elevate what might not have been a focus of attention by others".[10] Through an exploration of the field of Aboriginal and Torres Strait Islander health and medical research, by Aboriginal and Torres Strait Islander researchers, this work re-positions Euro-Western standard practices of research[11] whereby the predominately non-Indigenous researchers are the subjects to Indigenous research as defined by us.

Study design and data collection

A mixed methods survey was conducted nationally to examine Aboriginal and Torres Strait Islander community-controlled health organisations' (ACCHOs') experiences and perspectives of health and medical research. Electronic survey data were captured using REDCap (Research Electronic Data Capture) version 14. The survey was conducted between August 2022 and April 2024. Contact details for ACCHOs were obtained using readily available information from the National Aboriginal Community Controlled Health Organisation (NACCHO) website,[12] which identified 143 members of NACCHO. Where contact details were not available on NACCHO's website, individual ACCHO websites were used to obtain publicly available contact details. All ACCHOs were eligible to participate. The chief executive officer of each ACCHO, or their delegate, was invited to complete the survey as a representative of the ACCHO; they were invited via email and with a mailout paper copy of the survey.

Returned mailout copies were entered into REDCap manually. Networks of the investigative team were also drawn upon to invite key personnel within ACCHOs to complete the survey. The embedded knowledge translation activities of the research (including webinars, invited presentations and conference participation) also supported the recruitment process. Multiple engagement strategies were drawn upon, including the development of a project website and brochure explaining the project. Invitations were included in online newsletters to the Lowitja Institute members' network as Australia's only national community-controlled Aboriginal and Torres Strait Islander health research institute.

Outcome measures

Data were collected using a 33-item mixed methods survey. The survey was developed by the author team — who have decades of experience, expertise and recognised leadership in Aboriginal and Torres Strait Islander health and medical research in both institutions and the community-controlled sector — to ensure it addressed the study objectives. Survey items were pilot tested and amended according to feedback from Aboriginal and Torres Strait Islander researchers, communities and those involved in project governance to ensure they were culturally appropriate and acceptable and to ensure the survey effectively captured the intended information. Further information on development of the survey can be found in the study protocol.[13]

The nominated representative from each participating Aboriginal and Torres Strait Islander community provided data about service type and postcode. To describe their positioning (ie, their stance) and processes relating to health and medical research, community representatives were asked: "In general, how do you feel about research" (rated on a 5-point Likert scale, very negative to very positive); "Does your service have any formal processes for research approval and/or governance?" (with options yes and no); "If you answered no, do you have an interest in building formal processes for research approval and/or governance?" (with options yes and no); and "In general, has research been a benefit to your community?" (with options don't know, not at all, sometimes, often and always). Community representatives also rated the importance of 15 ethical principles on a 5-point Likert scale (not at all important to essential). Open-ended survey items asked about communities' experiences of health and medical research in the previous 5 years, including: the number of times they were approached to participate in research in the previous 5 years, the number of times they had agreed to participate in research in the previous 5 years, the number of times they had withdrawn from a project in the previous 5 years, and participation in Indigenous-led research. Open-ended questions were asked after each item to elicit more in-depth responses, with two additional open-ended questions: "What are the reasons your service has or would participate in research?" and "What are the reasons your service would not, or has not, participated in research?" Aboriginal and Torres Strait Islander communities' recommendations for how to improve health and medical research were captured by asking two open-ended questions: "Do you think there is anything needed to improve the conduct of Aboriginal and Torres Strait Islander research? (eg, particular training, resources, etc)" and "Do you have any additional comments about your experiences in research?" Demographic information about representatives was intentionally not collected due to concerns that representatives would be re-identifiable given the small number of eligible organisations.

Data analysis

To uphold the application of Indigenous methodologies, all data were analysed by the Aboriginal PhD candidate (FC) with oversight from the senior Aboriginal author with experience in mixed methods analysis (MK). Further guidance was provided by non-Indigenous researchers with experience in quantitative research (JB) and qualitative research (KB). Quantitative and qualitative data were analysed separately and integrated after each analysis through Collaborative Yarning[14] between the study team (FC, MK, KB and JB). Quantitative data were analysed using Stata/BE 18 (StataCorp) and are presented as counts and proportions. Open-text data were coded and managed using NVivo 14 (Lumivero) using a template analysis against ethical research criteria following steps described by Brooks and colleagues.[15] Template analysis is a diverse method that affords flexibility to be responsive to the collaborative yarning process between expert researchers, and to accurately represent community perspectives and experiences in line with the aims of the manuscript. After preliminary coding by FC, initial themes were discussed through collaborative yarning between the researchers to determine the final template to be applied to the full dataset.

Ethics approval

This research was developed in collaboration with Aboriginal and Torres Strait Islander researchers, ACCHO representatives, Aboriginal community members, and the National Health Leadership Forum (now known as the National Indigenous Health Leadership Alliance). The project upholds ethical principles of research in line with NHMRC[3] and Aboriginal Health and Medical Research Council of NSW (AH&MRC) guidelines,[4] as well as the Consolidated Criteria for Strengthening Reporting of Health Research Involving Indigenous Peoples (CONSIDER) statement.[16] Ethics approval was received from the AH&MRC Human Research Ethics Committee (1924/22), Australian Institute of Aboriginal and Torres Strait Islander Studies Research Ethics Committee (EO323-20220414) and University of Newcastle Human Research Ethics Committee (H-2022-0211). All community representatives provided informed consent for participation.

Results

Of the 143 eligible ACCHOs, responses were received from 53 representatives. It was identified that representatives of two communities completed the survey twice. The first quantitative responses from these representatives were included for analysis, and the duplicate qualitative responses were combined. This resulted in data from representatives of 51 communities (36% response rate) being included in the study. The profiles of respondent communities are provided in Box 1. While only one survey was completed per community (other than the two with duplicate completions), we are aware that some ACCHOs completed the survey collectively and two community representatives completed the survey over the phone with the research team. No responses were received from representatives in two small states and territories.

Data on processes and positioning in research are provided in Box 1. Most community representatives reported feeling slightly or very positive about research (37, 73%); however, 10 (20%) reported feeling neutral. More than half (33, 65%) reported having formal governance processes for research. For those without governance processes, two-thirds (12, 67%) were interested in

1 Community profiles and perceptions of research (51 representatives)

	Respondents
Community profile	
Service type	
Aboriginal community-controlled health service	45 (88%)
Aboriginal health service (not community controlled)	2 (4%)
Other community-controlled organisation	4 (8%)
State/territory*	
New South Wales or Australian Capital Territory	19 (37%)
Northern Territory	9 (18%)
Queensland or Torres Strait Islands	11 (22%)
Western Australia	6 (12%)
South Australia	3 (6%)
Victoria or Tasmania	3 (6%)
Perceptions of research	
Feeling about research	
Very negative	0
Slightly negative	4 (8%)
Neutral	10 (20%)
Slightly positive	13 (25%)
Very positive	24 (47%)
Formal processes for research approval and/or governance	
Yes	33 (65%)
No	18 (35%)
If no formal processes, interest in building research approval and/or governance processes	
Yes	12 (67%)
No	6 (33%)
Research of benefit for community	
Not at all	4 (8%)
Sometimes	21 (41%)
Often	13 (25%)
Always	6 (12%)
Don't know	7 (14%)

*Some states and territories have been collapsed to ensure anonymity of responses. ◆

developing them. The largest proportion of representatives reported that research is of benefit for community sometimes (21, 41%) followed by often (13, 25%), always (6, 12%) and not at all (4, 8%).

Participant perspectives of the importance of ethical principles are presented in Box 2. The top three ethical principles considered to be essential to be upheld in research practice by community representatives were: researchers sharing results back with community (45, 88%), translating research into policy and practice changes (37, 73%), and employing Aboriginal and Torres Strait Islander staff (37, 73%). Representatives also highlighted Indigenous data sovereignty and governance principles being

2 Importance of ethical principles (51 respondents)

Ethical principle	Not at all	A little	Moderate	Very	Essential	Unaware
Community identifies the research priorities	0	2 (4%)	4 (8%)	13 (25%)	32 (63%)	0
Community developing the research questions	2 (4%)	3 (6%)	11 (22%)	15 (29%)	20 (39%)	0
Research has community governance, advisory and decision making on the project	1 (2%)	1 (2%)	2 (4%)	13 (25%)	34 (67%)	0
Researchers enact Indigenous data sovereignty and governance principles	0	3 (6%)	2 (4%)	8 (16%)	37 (72%)	1 (2%)
Research agreements are developed between communities and researchers	1 (2%)	2 (4%)	2 (4%)	11 (22%)	35 (69%)	0
Research embeds opportunities for capacity building of communities*	1 (2%)	1 (2%)	6 (13%)	8 (17%)	30 (65%)	0
Research embeds opportunities for capacity building of the research team (ie, developing cultural capabilities)	1 (2%)	2 (4%)	7 (14%)	12 (24%)	29 (57%)	0
Community implements the research	1 (2%)	4 (8%)	14 (27%)	14 (27%)	18 (35%)	0
Research employs Aboriginal and Torres Strait Islander staff	0	2 (4%)	5 (10%)	7 (14%)	37 (73%)	0
Community oversight in analysing/interpreting the findings	1 (2%)	5 (10%)	9 (18%)	11 (22%)	25 (49%)	0
Reimbursement of costs to communities for partnerships and involvement	0	3 (6%)	5 (10%)	8 (16%)	35 (69%)	0
Community receives payment for sitting fees (ie, for research meetings)	2 (4%)	4 (8%)	6 (12%)	10 (20%)	28 (55%)	1 (2%)
Researchers share the results of the research back to communities	0	2 (4%)	2 (4%)	2 (4%)	45 (88%)	0
Community members are co-authors on publications and co-presenters on presentations	1 (2%)	3 (6%)	6 (12%)	14 (27%)	26 (51%)	1 (2%)
Researchers translate the findings into policy and/or practice	0	2 (4%)	3 (6%)	7 (14%)	37 (73%)	2 (4%)

* Data missing for five respondents. ◆

enacted (36, 71%) and research agreements being developed with researchers (35, 69%) as essential.

Experiences of health and medical research

Community representatives were asked about their experiences of being approached for research, participating in Indigenous-led research, and reasons why they have or have not participated in research. These findings are presented thematically below and in Box 3. In this article, we intentionally present all open-text responses to ensure Aboriginal and Torres Strait Islander community voices have not been silenced or removed in the process of producing this article (Supporting Information). As such, identifiers have not been used, so that we can ensure anonymity. Any potentially identifying information has been removed as indicated using bracketed ellipses and spelling and grammar have been edited for readability as indicated using brackets. The remaining content is presented verbatim.

Theme 1. Communities are over-approached to participate in research

Community representatives detailed being approached to participate in research more frequently than they were agreeing to participate, with many feeling bombarded by requests for research.

> We have been approached numerous times to participate in research however Aboriginal organisations are over it. Generally, mainstream organisations use Aboriginal organisations for research and expect to be privy to knowledge. Aboriginal organisations then spend a lot of time/resources with researchers and get nothing out of it but feel used. Research is great and needed however needs to be more culturally appropriate or situations approached in a positive manner to help build

relationships and capacity at Aboriginal organisations. Community 13, New South Wales

Theme 2. Proposals do not align with local community priorities

Research proposals often did not align with community priorities or needs, and community representatives reported often being approached in the later stages of research projects, without the opportunity to be involved in the project design. The additional burden of research requests was evident, with researchers failing to consider the time and resources required for communities to respond to requests or to participate in projects.

> Often approached just for a letter of support for ethics. Ability to influence or shape research is often very limited. Increasing numbers of research/evaluation projects that are seeking our support without the time to properly review and understand value/burden. The cost for an ACCHO to fully participate in research design, review, implementation and translation is still not well resourced either in research project funding or by other funders. Community 41, Northern Territory

Theme 3. Communities feel that Indigenous-led research centres their priorities, and is more appropriate to their needs and knowledge systems

Most community representatives reported they had participated in Indigenous-led research (39, 76%). Representatives reported that Indigenous-led research centred their priorities rather than the academic pursuit of the researcher, incorporated appropriate research methods and Indigenous methodologies that respect Aboriginal and Torres Strait Islander knowledge systems, and included local capacity building.

3 Experiences of health and medical research

Theme 1. Communities are over-approached to participate in research

We get asked and this consumes our time and takes us away from what we are funded to do. Community 32, Victoria

Just wanted to be clear that being approached doesn't translate to us accepting all. Community 35, Queensland

We have been approached upwards of 500 times over the past 5 years to be involved in research. Many of these are already developed projects. Definitely a tick-a-box process for many of them. Community 14, Western Australia

Researchers normally come with a fully formed research project and ask us if we want to be involved. Often, they are very pushy with timeframes and lack an understanding of how community organisations operate. Community 43, New South Wales

Theme 2. Proposals do not align with local community priorities

There is a sense at times of being bombarded. Things are changing, but the research organisations often come to us with a sense of entitlement and with themselves at the centre of the proposal. Often the proposals do not align with our priorities. Community 21, Northern Territory

Theme 3. Communities feel that Indigenous-led research centres their priorities, and is more appropriate to their needs and knowledge systems

[Indigenous] researchers have a better understanding of community needs, time demands, and more emphasis of knowledge translation and developing researchers' capabilities. Community 47, New South Wales

The Indigenous researchers from outside the community generally come with an innate understanding of the cultural protocols and respectful behaviours and generally formed a quicker and better bond with local researchers and the community. Community 21, Northern Territory

Theme 4. Communities were more likely to participate in research if it centred their priorities, involved genuine partnerships, and had direct benefit

The burden of the research was either resourced properly or we considered the research was worth the time/burden. Community 40, Northern Territory

Only participated when partnerships [were] perceived to be genuine. Community 45, Queensland

We also agree to research when researchers are willing to listen and understand our ways of working. Community 43, New South Wales

We have participated in research which directly relates to benefiting our community. We have also participated in research that benefits ACCHOs on a regional/state level. Community 23, Northern Territory

Theme 5. Communities will not participate in research due to lack of resources or if there are disingenuous partnerships

Researchers coming with their own agenda does not benefit community or mob, [not] relevant to our needs. Community 33, Victoria

Some research would place a burden on staff which we wouldn't be able to justify (eg, if multiple research projects on similar topics were happening at the same time which required staff involvement it would likely put an unreasonable burden on staff from the relevant program area). Community 41, Western Australia

When it impacts on clinical team members' time that restricts patient care. Community 48, Western Australia

We are more likely to reject projects that [are] presenting as partnerships but are not honest about actually only wanting a support letter [from] an ACCO. Community 41, Western Australia

ACCHO = Aboriginal community-controlled health organisation. ACCO = Aboriginal community-controlled organisation. ◆

Benefit is purely for community and not academia. Community 5, Western Australia

The research is usually more relevant to us and our service as well as more flexible to take into account our input. Community 41, Northern Territory

Theme 4. Communities were more likely to participate in research if it centred their priorities, involved genuine partnerships, and had direct benefit

Overall, community representatives reported they would agree to participate in research if there were clear and tangible benefits in a local context that positioned their priority research areas.

We believe in the value of research, especially if it directly benefits the community and the organisation. Community 39, Western Australia

Community representatives reported that research must involve genuine and trusting partnerships, with researchers understanding appropriate practices, and should preferably involve Aboriginal and Torres Strait Islander leadership. Importantly, the research must lead to improved service delivery or programs, and have meaningful, translatable outcomes. Representatives also noted that adequate resourcing

and flexible timeframes were considered essential both within internal organisational service capacity and provision of external resourcing by the research project.

Indigenous led and there has been amazing engagement since having Aboriginal researchers conducting the research and field trips. Community 40, Northern Territory

Theme 5. Communities will not participate in research due to lack of resources or if there are disingenuous partnerships

A lack of internal service capacity and resourcing to participate in research projects, as well as a lack of adequate provision of resources, were reported as significant reasons for not participating in research.

When research is not going to adequately fund […] for our participation. The lack of sufficient administrative costs with research projects is a major issue as often […] ends up subsidising the full cost of doing research from our core funds. The capacity to manage research projects is also a limiting factor with currently about 100 active research projects. Again […] has had to use core funds to create a research manager and senior evaluation officer position to enable us to manage research. Community 51, Northern Territory

Community representatives identified lack of genuine partnerships and trust in researchers as a key reason for not participating, noting that research practices often lacked transparency and respect for the community.

> Where a cultural lens is not at the core of the research — importantly, where the research looks like it will be TO us rather than WITH us. Community 21, Northern Territory

Communities' recommendations for health and medical research

When reflecting on their experiences, community representatives were asked about their recommendations for health and medical research. Open-text responses for these preliminary recommendations for health and medical research, grouped into five key points, are reported in Box 4. Representatives highlighted the need to consider adequate remuneration and resourcing for their participation, including appropriate timelines to conduct the research.

> Research projects should demonstrate how they will commit resources to community, and not expect to provide input or involvement from within existing resources. Community 47, New South Wales

Community representatives also reported that consideration should be given to communities being able to lead and implement their own research agendas. Community leadership was considered essential throughout all stages of research, including from conception of ideas to implementation of research and knowledge translation. This was reported to be best facilitated by Indigenous-led research both within the community through capacity building of local researchers and from external Aboriginal and Torres Strait Islander researchers partnering with the community.

> Researcher positions should be imbedded into health services to understand communities and their needs better. Capacity building within services. Community 31, New South Wales

Discussion

To our knowledge, this is the first national study to report Aboriginal and Torres Strait Islander communities' processes, positioning and experiences of research, as well as their recommendations to improve the ethical conduct of health and medical research. This study was conducted to privilege the voices and experiences of communities who are meant to be the beneficiaries of research, and who we know have had negative experiences of research since colonisation.[11] Concerningly, in this study, community representatives reported that unethical research practices persist that negatively impact their experiences of health research. We found that while representatives acknowledged the potential benefit of research and the majority felt positive about research, only a small proportion reported that research was always of benefit to their community. Community representatives in this study reported that researchers' approaches to early stage consultation, engagement, genuine partnership and research proposal development have the potential to negatively impact their experiences of research. Notably, these research processes are often required before application for funding and ethics approval, which indicates

areas for improvement to the assessment processes. These findings indicate that while ethical research guidelines cover critical areas of health and medical research, these are not being consistently implemented by researchers. Aboriginal and Torres Strait Islander communities call for community leadership, ownership and power to drive their own research agendas. We note that this work is grounded in the voices of communities, who are the experts of their own experiences and processes in research. Direct quotes from community representatives in this study are used throughout the Discussion to anchor our calls, and to be accountable to these expert voices.

> Community hold the answers — community governance, advisory and decision making is the most important thing. Community 50, Western Australia

Aboriginal and Torres Strait Islander leaders and researchers have long advocated for all research conducted with communities to be justifiable and of benefit as determined by Aboriginal and Torres Strait Islander people.[17] Our findings strongly echo that communities want to participate in research if it aligns with their priorities and needs.[18,19] Concerningly, our study found that community representatives report continued unethical experiences such as being approached after research establishment and in the later stages as a "tick-a-box process", without genuine intent to undertake research in partnership with communities according to their priorities. Ethical guidelines highlight that researchers must work in partnership with communities to develop research based on their needs and expectations to ensure positive outcomes.[20] Beyond ethical guidelines, researchers have also been guided and informed on the implementation of ethical research practices by Aboriginal and Torres Strait Islander leaders.[21-23] Publications such as *Ten principles relevant to health research among Indigenous Australian populations*,[24] published over a decade ago, have highlighted "community input and ownership" as key drivers in communities directing and leading research. Our findings indicate that the perceived limited benefit of research for communities could be influenced by the lack of implementation of ethical practices such as early and meaningful engagement to develop research questions and proposals.

The rights for Aboriginal and Torres Strait Islander people to govern themselves pre-dates existing colonial structures and their operating systems.[25] Community representatives engaged in this study reported either having or having a desire to establish internal governance structures for research. While community governance is articulated in ethical guidelines as a mechanism for upholding self-determination and control of research,[4] findings from our study indicate that the establishment of such processes is more likely to have been in response to the reported burden of being bombarded by research requests. Our findings coincide with evidence of Aboriginal and Torres Strait Islander governance models for supporting ownership, consent and control of research.[26,27] The Inala Community Jury has described how their governance model and processes have "inspired transformative research practice because it transformed relationships of power between Indigenous people, researchers and research institutions, privileging Indigenous voices, experiences and perspectives in informing urban Indigenous primary health care research".[28] In Western Australia, regional models such as the Kimberley Aboriginal Health Research Alliance[29] and the Pilbara Aboriginal Health Research Alliance[30] have been established recently to act as a mechanism to ensure research aligns with local priorities. Organisations such as

4 Preliminary recommendations for health and medical research

Key point 1. Adequate remuneration and resourcing, including appropriate timelines, are embedded in the research project

Relatively positive because I have worked, always, with Elders and leaders who have given advice and mentoring. These have been paid positions to acknowledge their specialist skills/knowledge. Community 17, Northern Territory

Renumeration for time. Community 28, New South Wales

Research projects should demonstrate how they will commit resources to community, and not expect to provide input or involvement from within existing resources. Community 47, New South Wales

Reimbursement of costs: it's important because they bring with them that cultural knowledge and expertise that researchers don't have. It's not necessarily "academic" but their knowledge is based on thousands of years of knowledge and that in itself has value, including life experience. Community 50, Western Australia

Key point 2. Funding for communities to lead and implement their own research projects

ACCHOs need funded research coordinator positions. Community 23, Queensland

Additional funding and dedicated research officer/manager roles to facilitate the process. Community 26, Queensland

Researcher positions should be imbedded into health services to understand communities and their needs better. Capacity building within services. Community 31, New South Wales

Resourcing ACCHOs to do the research, supporting ACCHOs to set research priorities and how to translate research outcomes. Supporting ACCHOs to embed research as a core part of the service. Community 40, Northern Territory

Key point 3. Community-led and Indigenous-led leadership throughout all stages of the research within communities and institutions

Let the community develop the research questions. Community 12, Queensland

Research "alongside" the community not "for" the community. Community 23, Northern Territory

Community oversight: that depends on having research capacity. Don't leave people in a position where they can't, they need to be confident with it and given the resources. The researchers need to acknowledge that even though someone may not have the same capacity or experience as them in analysing data, sometimes the simplistic way of looking at data is the right way rather than trying to read too much into numbers. Community 50, Western Australia

Our aim by 2024 is to be in control of our research agenda by releasing an EOI and seeing which institutions want to partner with us to conduct the research that we want done. Community 21, Northern Territory

More opportunities and promotion of Aboriginal researchers. We need our own research hub! In each state and territory, Aboriginal ethics groups, etc. Community 39, Northern Territory

Entry-level funding or recognition for Aboriginal people to come into the field, research and evaluation pipeline. They make great researchers. Aboriginal people are the most over-researched, and they are, but when they are put in charge of it all, they are excited and want to do it. It's a dominant narrative that they are sick of being researched, but really, it depends. Community 50, Western Australia

Research employs Aboriginal staff: this shouldn't just be to do the recruitment or admin work or ethics consenting process because they are the locals and aren't given any insight into the overall project such as analysis and reporting. It comes back to capacity-building stuff of Aboriginal and Torres Strait Islander people in the research and evaluation space. Too often we are employed to only give a welcome to country, not considered we can do this other stuff. Community 50, Western Australia

Key point 4. Culturally appropriate and respectful research practices are embedded, and clear benefits are identified

My experience is that research is widely mistrusted, considering a long history of being the "subject" of research. Community 4, Western Australia

We need to turn it on its head and direct the research. Community 14, Western Australia

I think linking in with Aboriginal [...] is the way to get the Aboriginal community involved, and the research needs to be done in culturally safe space. I think only Aboriginal people should be doing Aboriginal research; it's fine for others to support the process, but only Aboriginal people understand Aboriginal people. Community 18, New South Wales

Until our people are really listened to and given the power to make decisions for ourselves without the imposed institutional racism, nothing will improve for our people. Community 18, New South Wales

It's tiring working within institutional ways. Community 38, Queensland

Cut out the racist attitudes and make research more understood and therefore accessible. Community 45, Queensland

Key point 5. Indigenous data sovereignty principles are enacted, and research findings are translated into policy and practice outcomes

The principles of Aboriginal data sovereignty need to be more widely adopted. Community 41, Western Australia

Lessons learnt from previous research and researchers not sharing the knowledge they gained from the research, drawing a line in the sand that the information you collect belongs to the community, you may use it but it's not yours to keep. Community 50, Western Australia

Practice of converting research into policies. Community 23, Northern Territory

ACCHO = Aboriginal community-controlled health organisation. EOI = expression of interest. ◆

the Central Australian Aboriginal Congress and the Kulunga Aboriginal Unit in the Kids Research Institute Australia have developed localised standard-of-practice guidelines to advise researchers of their expectations of how Aboriginal and Torres Strait Islander governance, involvement and control must be embedded in research approaches,[31,32] including the use of Indigenous methodologies also reported by communities in our study. Further, communities are clearly articulating their research priorities and processes to external researchers.[33] Our findings align with the critical importance of such structures.

While the establishment of these governance processes from communities is a powerful testament to Aboriginal and Torres Strait Islander people taking matters into their own hands, this alone is not sufficient. Current governance structures inevitably continue to add to the layers of burden experienced and reported by communities as the administration of these processes falls to communities to operationalise. Our findings indicate that researchers and institutions continue to benefit from the burden experienced by communities. Furthermore, unlike universities and institutions, there is no current investment for communities to establish and maintain research governance systems regardless of their involvement and this being outlined in all relevant ethical guidelines.

> Research projects should demonstrate how they will commit resources to community, and not expect to provide input or involvement from within existing resources. Community 47, New South Wales

Overall, Aboriginal and Torres Strait Islander community representatives who participated in our study reported the financial burden of being involved in research and highlighted the lack of funding available directly to them to conduct their own research. While previous research has highlighted that researchers report that funding and timeline restrictions are a barrier for implementing research in Aboriginal and Torres Strait Islander health,[34] limited reports have articulated Aboriginal and Torres Strait Islander experiences. Our study showed that communities and organisations are using core funding to keep up with the demands of research. Acknowledging the continued growth in Aboriginal and Torres Strait Islander health research,[35] alongside increased investment from a range of funding bodies[36,37] that is expected to continue, these findings indicate high burden and risk to communities that require attention. National consultations regarding Aboriginal and Torres Strait Islander health research[38,39] have highlighted promising improvements for institutional funding, but consideration of how funding might be directed to the community-controlled sector to lead research is lacking.

Aboriginal and Torres Strait Islander communities have always been at the forefront of ethical research practice, driving the development, implementation and enhancement of values, principles and guidelines since the adoption of the Declaration of Helsinki in Australia. Advocacy to improve research is not new knowledge.[40] In 1982, landmark statements and recommendations were made by the Central Australian Aboriginal Congress in relation to the ways in which Aboriginal and Torres Strait Islander people should have control, leadership and ownership of the research that affects them.[1] Almost five decades later, findings from our study highlight that there has been limited improvement in upholding these rights, with little benefit and few meaningful outcomes from research conducted in Aboriginal and Torres Strait Islander health and medical research.

> Research funding continues to encourage bad behaviour by expecting researchers to do the design work prior to receiving funding. This limits co-design and community ownership. Community 40, Northern Territory

Our study showed that communities are actively calling to flip the current status quo of research where they are currently considered the passive participant, to actively driving and leading their own research agendas. Community representatives

that participated in our study have echoed statements made in 1987 that Aboriginal and Torres Strait Islander community-controlled organisations must have control of research funding to uphold ethical practices of researchers.[41]

The current major funding opportunities have not been established with considerations for community-controlled organisations to administer those funds. This actively excludes communities and limits their abilities to lead their own research agendas. Currently the Lowitja Institute and recently the Medical Research Future Fund have led targeted calls with considerations to the application and administration processes to fund community-controlled organisations.[42,43] We urge other funding bodies to address their critical role in ethical research practices in Aboriginal and Torres Strait Islander health and medical research.

Limitations

Our study is reflective of 51 Aboriginal communities nationally. We note that the mode of a survey, and the questions asked, may have limited the responses from communities, particularly the questions regarding the numbers of requests from and responses to both researchers and research requests. During the recruitment process, some community representatives reported challenges answering the questions in the survey as they were not sure who in the service would hold all the contextual knowledge. Further, it may be a limitation that demographic information about the person or collective of people completing the survey was collected, as respondents may have been concerned that they would be re-identifiable upon reporting of the study findings. The survey was developed based on a review of peer-reviewed literature and ethical guidelines, and received extensive community feedback and pilot testing; however, the absence of validity and reliability testing should be noted as a limitation. We acknowledge that Aboriginal and Torres Strait Islander communities are not a single homogenous group, and it should be considered that the voices and perspectives presented in this article are unique to the individual communities from which they originate. It is likely that the responses in our study reflect communities with more positive experiences of research, while negative and harmful experiences may be underrepresented. Thus, our study is considered a snapshot to generate further national dialogue on the ongoing review and refinement of Aboriginal and Torres Strait Islander ethical research practices and processes.

> Until our people are really listened to and given the power to make decisions for ourselves without the imposed institutional racism, nothing will improve for our people. Community 18, New South Wales

Conclusion

Aboriginal and Torres Strait Islander people, communities, leaders and researchers have been at the forefront of advocating for improved research practices that centre their rights to ownership, control and leadership in health and medical research. Despite their voices being active in the field for the past four decades to ensure research is respectful and beneficial, and has tangible outcomes, communities continue to have negative experiences of research that are incongruent to current ethical guidelines promoting otherwise. These unacceptable and unethical experiences continue to burden and silence Aboriginal and Torres Strait Islander communities. We

urgently call for researchers, funding bodies and institutions to examine current funding and research structures and embed systems of transparency that are accountable to Aboriginal and Torres Strait Islander communities. Pivotal to this are the rights for Aboriginal and Torres Strait Islander communities to be repositioned beyond sentiments of spirit and integrity, whereby there are systems to ensure they have the power to direct and lead health and medical research that prioritises them into the next decade.

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Supporting Information

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