Supporting Information

Supplementary methods and results

**This appendix was part of the submitted manuscript and has been peer reviewed.
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Table 1. Qualitative responses from community representatives: illustrative quotes

Experiences of Health and Medical Research
Theme 1 – Communities are over-approached to participate in research
- We get bombarded by emails often. We are a very small organisation and do not have the staff resources to engage in research most of the time.   - As a metro ACCHS we are frequently approached, often at the end when the project is already designed and researchers are just seeking support letters for ethics. We decline most of these projects.   - 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.   - 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.   - Just wanted to be clear that being approached doesn't translate to us accepting all.   - As a large Aboriginal community-controlled organisation, we receive many requests to partner on research projects. Requests come from state and national university-based researchers to NGO organisations. PhD students also request our participation. Most researchers are not Aboriginal, but the research might interest us because it is in areas relevant to our programs and services. Most research is still from a western focus, though increasingly researchers are attempting to include the voices of Aboriginal people, whether in interviews or in co-design. Sometimes researchers approach us because they are required to receive endorsement/support letter from an ACCHO/[ACCO] for ethics approval, in addition to accessing participants.   - Potentially 30 (times approached). What's in it for us?   - We are approached almost weekly, approached all the time, couldn't put a number on it. The […] and […] are further advanced in terms of having processes to assess research applications and as those places have got more organised, […] has been getting more requests because they are seen as an easier place to get into. A lot more research being done around urban Aboriginal people, we are seen as the go-to. We have started to become pickier about which research we get involved in, but don't have a formal process.   - 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.   - As a metro ACCHS we are frequently approached, often at the end when the project is already designed, and researchers are just seeking support letters for ethics. We decline most of these projects.   - All the time being asked to participate at the last minute. Just want our data and name so it can be ticked off.   - Very regularly – some very unprofessional and some well organised with ethics approval. We have come to a conclusion that the best measure for the organisation is to ask what is in it for our organisation and communities, if this is not obvious it's a no.   - We are usually approached once the research grant has been gained with little or no engagement prior to this.   - Approaches have been made by known contacts. We will work with researchers who provide culturally safe research practice/methodologies on topics that are relevant to our communities. We engage with Elders and leaders to gain their approvals.   - It's always orgs or services have received funding for research and looking to partner with [an] ACCHS.   - 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.   - 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.   - Many expect provision of resources with little reimbursement and little consideration of the need to provide essential services to our community. Have had to resort to placing a moratorium on our service being involved in new research projects due to the over burden of research.   - As a very small ACCHO we have limited resources for research approval and/or governance. We also have to limit the amount of research support that we can manage with our limited resources.   - We get asked and this consumes our time and takes us away from what we are funded to do.   - The […] manages the […] and the […] which considers Aboriginal health research proposals from research institutions.   - We are connected to "Mother Service" who supports/operates a Research Governance Group.   - Any requests for research go to all of management and then escalated to the Board for approval. We have 5 working relationships with different universities, they consistently work with […]. Have some additional requests for research.
Theme 2 – Proposals do not align with local community priorities
Needs to be according to the community's health priorities, health services need to take a moment to decide what is important for their service and only take part in research that has benefits for their community.

• 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.
• The nature of the approaches has improved in the last 2 years and we now either have in place, or are close to having, research MOUs with the major institutions. However, on the whole, the research institutions want to take as much as they can and give as little in return.

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

- Benefit is purely for community and not academia.
- Community feel it will benefit us.
- The needs of the community are listened to and prioritised.
- The research is usually more relevant to us and our service as well as more flexible to take into account our input.
- This research was designed by our communit[y's] priorities for research.
- Indigenous led because it's our priority.
- Opportunities to be on advisory committees.
- Aboriginal leadership.
- Career Pathways was all Aboriginal led. Led by us with university support. Roughly 50% of projects have Aboriginal leadership.
- This is not always as good as it seems. Ironically many urban-based Indigenous mob (and I am one) come to remote places like […] with a sense of superiority and paternalism. We are striving for […] led research.
- Component for research projects now require them to be Indigenous led and they will always tick the box and say that the leadership is there, but it doesn't mean that it's grounded in the community. The yes/no thing, depends what level you are looking at in terms of the extent to how it is grounded in COMMUNITY leadership, but it might not line up so well with the interest of […] or the community. This is part of what we want to look at with the governance structure, coming up with our own terminology about what is community led vs what "looks" Aboriginal led.
- Participation action research.
- Often involves co-design.
- Co-design and collaborative approach.
- Decolonised research methodologies.
- Positive strengths-based approaches.
- Flexibility, responsiveness to the community and taking into account things that are happening in the community – e.g., respectful of sorry business and other cultural obligations that may be impacting the research participants.
- [Indigenous] researchers have a better understanding of community needs, time demands, and more emphasis of knowledge translation and developing researchers' capabilities.
- Greater understanding from the researchers about Aboriginal health and cultural safety and good communication protocols.
- More culturally appropriate.
- 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.
- Indigenous-led research has a greater awareness of issues, culture and less "explaining" is needed compared to a more mainstream approach.
- Proper code sign following protocols and connection with the community!
- I was able to feel very comfortable and form a good connection with him because finding […] people down south is not common.
- Once a mutual cultural connection was formed, I feel I was able to give more lengthy and personal discourse.
- Understanding Aboriginal ways of knowing, being and doing.
- Mob are much better to deal with and I feel like I am supporting them.
- Cultural[ly] safe, community minded.
- We're black so all our research is led by mob.
- Indigenous led, the research team understood our ways of working.
- Pay for local mob employment and research training.
- Develop researchers capabilities.

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

- Aligned to our priorities.
- Can see the relevan[ce] to organisation and communities.
- Some don't fit out remit, research must be relevant to us.
- Depends if the research meets our needs, first and foremost.
- Sometimes the research will investigate issues which will be relevant to the services we deliver or issues that are facing our clients.

- Relevant to strategic objectives.
- The research aligned with our values.
- Research aligned with our values.
- Aligns to our priorities.
- If it is a[n] area of concern in the community.
- Opportunities to explore solutions for our health challenges: – mental health needs – suicide prevention – access to IT – telehealth opportunities.
- Relevant to our community and organisation.
- Relevant to our health needs.
- High need based on population/health data.
- Addresses local health priorities/needs. Helps to further identify change/implementation of strategies.
- It's important to community. Community led. Address community priorities.
- Less often we participate in other projects that lack co-design or Indigenous leadership, except when they are around a topic that we can see a need for [in] our community.
- Good Aboriginal leadership and control.
- I like to support Aboriginal researchers.
- Directed by Elders.
- Aboriginal researchers.
- To support Aboriginal researchers.
- Indigenous led and there has been amazing engagement since having Aboriginal researchers conducting the research and field trips.
- We have participated in research that has been co-designed with us, or has strong Indigenous leadership.
- […] potentially acting as the regional lead around research.
- At the moment, there is a […] research committee (non-Aboriginal). They held a forum last year and they were talking about Aboriginal research and had a non-Aboriginal research organisation to come in and talk about it. We asked them why this was happening, it's ridiculous. We don't want another group telling us that we don't know about Aboriginal research. We are the experts, even though we haven't established a solid foundation for it. We know we are the experts in that area.
- Commitment to be involved in research from the Board. Opportunity to guide relevant research for our service and the community.
- Local employment component.
- Opportunity for professional development.
- Funding research officer positions.
- The ACCHO could build researchers in house.
- If it were to capacity build at our organisation.
- […] health would benefit from having frequent research as it's an ACCHO and there are always opportunities for people to become [an] AHW/AHP [trainee] and that's even without completing school. So frequent education is vital as it's also [a part] of closing the gap. In order to close the gap in health and education is by closing the gaps within ATSI Aboriginal community-controlled organisations.
- Provide broader community benefit such as capacity building and employment.
- To train and employ Aboriginal researchers.
- We felt we had the time, resources and knowledge to be able to participate.
- We have internal capacity.
- It takes a lot of time and needs funding for a dedicated research coordinator position.
- Length of time it will take to complete the survey or research project.
- Limitations are usually related to staffing and cost.
- They were projects that we knew we had the capacity to provide a worthy contribution. Capacity includes human, financial and physical and knowledge resources.
- The burden of the research was either resourced properly or we considered the research was worth the time/burden.
- Demand of involvement.
- Sometimes feel obligated.
- Pay for our time and knowledge.
- If no drain on limited resources of organisation.
- We only approve projects that have funding to reimburse client interviewees.
- Other services we trust are involved.
- They have been examined and endorsed by the […] body including CEOs of ACCHS and their Boards.
- Agree based on relationships.
- We get along with certain researchers, enjoy working with them, and trust that they will deliver what they promise.
- Only participated when partnerships [were] perceived to be genuine.
- Good engagement practices that clearly have a positive impact on Aboriginal health and wellbeing that we were happy to share.

- Not just an academic exercise and to be never used or heard from again.
- Where there is research that is reflective and shows that the researcher is genuinely engaging with how the research (process and content) can empower Aboriginal people, we are interested in supporting this type of research.
- We also agree to research when researchers are willing to listen and understand our ways of working.
- Is co-designed and collaborative.
- Methodology acceptable to Board and management.
- Meaningful responses and willingness to share truthful and deep/rich stories/responses.
- We prioritise research that values Aboriginal ways of knowing and is Aboriginal led. We have a process to vet potential partnerships.
- We have participated in research that has been co-designed with us, or has strong Indigenous leadership.
- Good benefit can come from projects done well.
- See the alignment and potential benefits of the project.
- 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.
- The research projects reflect interventions that are urgent or ongoing needs for our communities.
- Because we felt that the long-term benefits to […] outweighed the short-term costs.
- We believe in the value of research, especially if it directly benefits the community and the organisation.
- As a tool to do thing[s] better or to understand what is happening. Also to show that we are doing things well and there is strength within the community.
- We value providing the best quality health care for our community and research done well can ensure this is always provided in the best way possible for the benefit of our community.
- To better understand the real needs for community holistically.
- To benefit community members and health outcomes. Provide direct links between research organisations and community members.
- To improve outcomes for communities. Better understanding for community.
- Had real value in improving outcomes, systems and that affects communities.
- Can be used practically.
- Can inform policy and direction in a positive way.
- Improve health outcomes, assist with policy and procedures.
- To increase the wellbeing of our community.
- Potential for improvement of health outcomes.
- To close the gap. Truth telling.
- To get answers to questions that will lead to improvements in practice that will lead to improved outcomes for […].
- To be of benefit to the community.
- Want to help the people in the community.
- To better our understanding of health problems affecting the community, to improve the health outcomes of community members, and to improve the services [our] organisation is able to provide.
- We have participated for funding purposes to benefit the community we service in order to give a better service delivery.
- Benefit to community. If goals align with organisation goals.
- If there is benefit to the community.
- To inform service delivery and/or to inform health profile of the community.
- To be able to be evidence-based facts and finding[s] so as to influence government spending and policy development.
- Trying to get better health assistance for our communities especially our Elders, the lack of doctors is a very hard thing to get to the local areas in which they are really needed for our Indigenous people.
- When it increases the evidence base for service delivery/systemic transformation with urban Aboriginal health.
- Because we have formed the view that the benefits outweigh the costs.
- To build evidence of practice, to evaluate impacts, to strengthen service delivery, to improve health and wellbeing outcomes of our clients.
- Positive outcomes for future service delivery.
- Good research can influence/change policy – policy change can improve systems – good systems that are informed by research that is from community can make a profound change in outcomes for people.
- Improving health and wellbeing in some way.
- To provide better health outcomes for Aboriginal people.
- It is to improve the quality of our services and programs, to test out innovative new services and programs, to build the evidence base for action on the broader socio-economic determinants of health, to strengthen Aboriginal community controlled health services and demonstrate their impact, to train and employ Aboriginal researchers etc etc.

- The […] I believe should be involved because it is truly community run and Aboriginal voices will be heard. ORIC have too much power over other Aboriginal organisations and community do not have real self-determination or empowerment.
- Meaningful and useful/translatable outcomes.
- Only agreed if research was relevant and could provide tangible/useful outcomes that would improve practice. Only participated if the project was mutually beneficial.
- We undertook the lead in the research and the outcomes [were] for the community to use and in a format they could.
- We will only participate if it benefits our community or if it's something we want to support and [participate] in as [it usually] helps inform service delivery.
- They will all contribute to improved service outcomes.
- […] has been able to partner with researchers to improve the quality of our services and programs and help address to the socio-economic determinants of health.
- Evaluations with external researchers on our […] readiness program. […] support service and others have played a key role in getting governments to continue major funding.
- Research is helping to improve the quality of our clinical services and programs as well.

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

- Not relevant. Duplication of projects.
- If the research project does not apply to us.
- Proposals do not align with regional Aboriginal health priorities.
- External priorities without proper consultation with health services and communities.
- If it didn't align with our values.
- Not relevant.
- Researchers coming with their own agenda does not benefit community or mob, [not] relevant to our needs.
- When a proposal is not in accordance with our research strategic plan.
- No resourcing to manage the portfolio.
- Limited resources would be a possible reason.
- Not all have progressed, but this is usually due to lack of funding or failure to secure grants.
- Could not commit the [time] required to attend governance meetings.
- Unable to complete due to researchers leaving the role early and not being able to find a suitable replacement.
- Change in capacity – service delivery demands/COVID-19.
- At times the workload and my times are too busy. Also, research has often been scheduled through NAIDOC week when it is not easy to attend or support.
- Rather than withdraw, we suspended the project because of difficulties recruiting to positions that could provide support to a research officer.
- We had competing demands. Grew too quick, will only take on 4–5 projects at a time. Didn't want pressure to deliver or strain relationships with universities. It was at the early stages of development.
- Change of leadership.
- Too small, no staff or time.
- Lack of time and staff.
- Inconsistent changes to management and to work. Lack of leadership or basic interest.
- Time poor.
- I have to weigh up the time of completing the research survey and my mental capacity at the time. If the research piece is too emotive or too time consuming, I will not participate in the research.
- The main limiting factors are financial reimbursement and staffing as all research requires time and resources.
- Lack of knowledge, alignment, and time and resources.
- Lack of community involvement and recognition; no funding contribution or payment to community researchers; no […] leadership in the research; no perceived benefit; poor previous relationships.
- Some research would place a burden on staff which we wouldn't be able to justify (e.g. 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).
- When it impacts on clinical team members' time that restricts patient care.
- The research committee criteria for assessing a research project will be about corporate risk, funding and resources involved. […] is extraordinarily busy, so we can't take on anything that will add burden. Alignment with […] values.
- 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. The return on investment however has been immense.
- There was no interest from the researcher/university to contribute to building research capacity equally.

- Partnership was not genuine.
- No local consultation. No local involvement. Tick-a-box process. Aboriginal investigators listed on projects without their knowledge
- Not collaborative. Where our service would be identifiable.
- Tick a box to access funding.
- Haven't been given the opportunity.
- Something we are working on as an organisation is holding researchers to account when things aren't done appropriately.
- Could not provide ethics approval.
- Generally, research projects which are body-part specific or driven by academic interest rather than reciprocal agendas.
- None that I am aware of, but there are a couple where we have come close due to the arrogance, lack of respect and entitlement of some researchers.
- One project overstated […] involvement in the research and was misleading in the description of […] endorsement and level of cultural oversight. This was experienced as the researcher using […] name to make all sorts of untrue claims about the research. In light of this, […] requested our name not to be used in the report and that a number of corrections be made as feedback.
- No transparency in use of data.
- It became culturally unsafe to be part of it.
- 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.
- Lack of trust in researchers.
- Inexperienced researchers (have not worked previously with Indigenous communities). No Aboriginal leadership in the research team.
- Additionally, any research that may be controversial or not reflect Aboriginal and Torres Strait Islander health positively would not be something we would want to participate in.
- Topic over-researched with no cultural competency.
- No […] leadership in the research.
- If the research scope is too narrow, has a high burden, doesn't allow for input into the design and implementation, doesn't translate to improved practice, policy or services.
- 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. Also, less likely to partner with research that has only considered inviting an ACCO involvement at the last minute – when they need it for ethics approval – once the whole project has been designed etc without any community input in those early stages.
- We would not participate in research that is unethical, isn't a priority area for our community, lacks an understanding of our ways, doesn't have any benefits for our community, and that comes to us last minute for involvement in a tokenistic way.
- More of the "bad old days" repeated research about us without us! Unfortunately, this still happens because of a pre-conceived colonial ideal that "blackfullas don't know what's good for them". Therefore, it's up to the mainstream to take control.
- Lack of trust. City centric.
- Became clear no benefit to the organisation or clients.
- Generally, research projects which are body-part specific or driven by academic interest rather than reciprocal agendas.
- Not aligned with our health priorities.
- No benefit for our service or community. Data gathering exercises that don't benefit community.
- Expected outcomes not clear.
- No ethics approval. Appear to be in the benefit of researcher or institution only – no real connect or use for organisation, doctor, or community.
- We feel used and get nothing out of it nor does our community.
- Where the perceived balance of benefit is with the researcher.
- Because it doesn't really help the community in a lot of ways! […] basically, just helps people better [their] career in academia!!!!
- It is a government body or mainstream service asking specific questions in regard to Indigenousness. Our people, myself included, have given enough information to mainstream and government services about our culture. I am not giving them any more information especially given that I am not 100% clear on how this information could be portrayed in their research project. 2. I am unlikely to give information to mainstream services specifically because I feel mainstream services gather data from Indigenous people to support their own narrative. Specifically, they use our data to support funding grant proposals which leads to mainstream services being funded to deliver programs for Indigenous communities. I feel confident in saying that Aboriginal controlled organisations are the best fit to deliver Indigenous services to our own mob. 3. If I don't feel that my professional practice/life experience to date is going to benefit a specific research piece than I won't participate.
- Topic over-researched with no cultural competency.
- Lack of community understanding. No direct benefit to local community.

- Didn't assist with what the organisation/community wanted to achieve.
- When agenda is driven by academic terms of reference which does not meet our needs. i.e. we are not objects to be studied; we are people who seek societal change.
- Lack of community involvement and recognition; no funding contribution or payment to community researchers; no […] leadership in the research; no perceived benefit; poor previous relationships.
- I would only assume if it had no impact to our community, scope of practice and values.
- If the research scope is too narrow, has a high burden, doesn't allow for input into the design and implementation, doesn't translate to improved practice, policy or services.
- We are highly unlikely to partner again with organisations/partners that do not deliver on what they promise, such as failing to provide us with deliverables. We do not go ahead with research that seems tangential to our programs or client base. We would not go ahead with research project's whose agendas are distant from the community or have not been endorsed by the community in some form. We've rejected those for whom recruiting Aboriginal participants seems like an afterthought/last minute addition because they can't guarantee the safety of our clients, or they cannot pay them.
- We would not participate in research that is unethical, isn't a priority area for our community, lacks an understanding of our ways, doesn't have any benefits for our community, and that comes to us last minute for involvement in a tokenistic way.
- Proposed research lacks relevance.
- Some services have sought [our] organisation's support on a project to strengthen their grant application, however, have not provided any tangible benefit to our organisation through resourcing or sought to have meaningful engagement.
- Not a clear value in the research. I think also, in some instances we have alluded to it before, researchers have come in and used information to paint not a very good picture of […] or […] Aboriginal community. So, we know that our CEO at the moment has tried to re-build her trust in researchers and that could play a part in having trust.
- Are we going to see good outcomes. Assessment and opinion of the community panel. We wouldn't take anything to the community panel unless we were sure that the other things were in place. We also want to include capacity building. Track record of the researchers for taking findings back to the community, what can we see from their previous work and doing good knowledge translation. We are still fleshing it out but got quite clear criteria coming.
- When ownership of research and information gathered is not retained within community.

Preliminary Recommendations for Health and Medical Research

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

- Have had some not great experiences with team that promised tangible and visible information to improve CQI and quality team outcomes in primary care – took a lot of time and resourcing without any usable outcomes and published improving researchers' careers. No benefit to clients or community.
- 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.
- Renumeration for time.
- Funds need to go directly to Aboriginal researchers and the communities that they are working with and in.
- Research projects typically move to a schedule which meets the deadlines decided by the researcher and the funder. This is unlikely to align with the timeframes that suit community. We have had positive experiences where the funder has wanted to support community-led research, which included not having pre-decided timeframes and methodologies. This requires sitting in uncertainty which can be uncomfortable, especially for researchers. It requires a giving up of control, which can be a challenge to the identity and traditional role of the researcher. Where this can be done it seems there are ways to find genuinely collaborative approaches.
- Research projects should demonstrate how they will commit resources to community, and not expect to provide input or involvement from within existing resources.
- 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.
- Payment for sitting fees: Essentially yes, but there might be ways of doing it that are more finessed. e.g., in the […] community, they share the money and resources, so you might offer something that you do for their family. If running a project community-wide or it sits on top of projects already running, they are already benefiting from being involved in a project and then all the good stuff that comes out of the research will benefit the community and can argue for more funding or support.

Key Point 2 – Funding for communities to lead and implement their own research projects

- ACCHOs need funded research coordinator positions.
- Ideally it would be good if there was [an] initiative where there is a peak funding body [who] provides funding to every Aboriginal and Torres Strait Islander ACCHO, but only if they are registered with that peak funding body and follow the guidelines around what that peak body surveys and researches. And then the Aboriginal and Torres Strait Islander ACCHOs become a Registered Training Organisation that can facilitate all the training and research projects. In this way funding is saved for research, professional development.
- I believe every ACCHO should be under one peak body and are their own Registered Training Organisation so the above can happen.

- It would be great if there was one source that collated all the Aboriginal-controlled research that we can pay as an organisation to read (look honestly, this may already exist, and I am uninformed on the matter).
- Additional funding and dedicated research officer/manager roles to facilitate the process.
- Researcher positions should be imbedded into health services to understand communities and their needs better. Capacity building within services.
- More learning for university about what AMS[s] do, where research fits with us. Developing a research team in an AMS.
- 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.
- My dream is that we secure research funding and then we call for researchers to come and undertake that research. Would like to learn from others who have been down the path of doing their own governance processes

Key Point 3 – Community and Indigenous-led leadership throughout all stages of the research within community and institutions

- We were recently approached by a student who wanted to look at our data sovereignty protocols – only service approached/involved which would make us identifiable. No clear benefit to community. No Aboriginal governance for project. No consultation about our interest or desire to be involved prior to presenting a research outline.
- Yes, to create opportunity for community involvement: incentives for research participation.
- [More] community engagement and consultation with Aboriginal and Torres Strait Islander groups.
- Let the community develop the research questions.
- Involving community.
- Research "alongside" the community not "for" the community.
- Government listens to universities, there is a benefit to our people by partnering with universities.
- As mentioned, we have a process for vetting potential partnerships. Partnerships have to be approved by our executive, and approval is based on a number of things such as whether the project is a good fit, whether we have capacity to assist, what the level of community involvement/endorsement has been for the project.
- More Aboriginal research participants.
- Community have [to be] at least involved in the conversation. Community hold the answers – community governance, advisory and decision making is the most important thing. It's important to have a community working group/governance group for this. Really important that they have a say and are decision makers in the whole process, and they get to control what happens with their data.
- 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.
- Must be community-determined and driven. Researchers must agree to principles governing Aboriginal health research in the […] Alignment with priorities, development of capacity – co-design, training.
- Recognition in publications, payments for resource inputs and advice, consultation on outcomes, advocacy support for funding of findings.
- The ideal situation would be for Aboriginal and Torres Strait Islander organisations to set the research agenda for their organisations and seek expression of interests from research institutes to partner. Governance needs improvement, including the development of balance[d] research agreements based on a respectful perspective and that recognise a minimum of equality of standing of the partners.
- It is getting better, but still a long way to go. Large research organisations are slowly starting to realise that the tide is turning and that their modus [operandi] needs to change. My organisation is taking the bull by the horns and setting the agenda. However not all ACCHOs will be able to do this so will need support.
- Proper co-design! It would be great if the community could choose what the[y] need rather than getting told what the[y] need!!!
- Long-term relationships are critical. Researchers show reciprocity for community priorities. There is a lot to be gained from relationships with universities.
- Our aim by 2024 is to be in control of our research agenda by releasing an expression of interest and seeing which institutions want to partner with us to conduct the research that we want done.
- 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.
- We would like to see more capacity-building opportunities built into research including training resources specifically for AMSs. It would also be good for more opportunities for AMSs to lead our own research and not have all the funding go to uni's. Lowitja [Institute] is the only example we have seen so far of this happening.
- Community led is best practice.
- Needs to be Aboriginal led.
- Important that community are part of the implementation, if you have all the other things right, this flows along. If it's come from grounded research, the community should have oversight of what changes in practice might look like (e.g. clinical work). Make sure there is community leadership around the whole design of the project including implementation.
- Co-authorship: in essence, researchers are telling someone [else's] story. The story needs to come from the people that the story is about.

- There needs to be more upskilling of Aboriginal and Torres Strait Islander people in research practices to be able to lead the way in all communities.
- More mob involved in research.
- Employment opportunities for community members
- Training with culturally knowledgeable Aboriginal/Indigenous researchers.
- I would love to see more of it and more Aboriginal and Torres Strait Islander-led research.
- A lot of researchers and institutions come to us in the guise of "capacity building" when the reality is we do more capacity building with them around governance, Indigenous methodologies etc.
- More opportunities and promotion of Aboriginal researchers. We need our own research hub! In each state and territory, Aboriginal ethics groups, etc.
- At the same time, we recognise that Aboriginal people trained in research are in short supply. This is why it's important to broaden the definition of researcher, and to see the divide between researcher and participant as being more porous than we would normally think.
- Having some capacity building for researchers which really encourages them to challenge their own assumptions about what Aboriginal-led research really means, and to understand the immense power that they hold by virtue of being the researcher. It seems that some researchers think they are at the cutting edge and don't need to do more, but from our perspective they can actually be quite unthinkingly controlling and dismissive of the idea that Aboriginal-led research means that they, the researcher, will not be in control of all aspects. Capacity building which really encourages the researcher to consider their identity as researcher, and what they think that means to them and how that plays out in decisions large and small.
- We would like to see more capacity building opportunities built into research including training resources specifically for AMSs. It would also be good for more opportunities for AMSs to lead our own research and not have all the funding go to uni's. Lowitja is the only example we have seen so far of this happening.
- There's a bunch of wraparound support, there is often funding for Aboriginal students in Honours, post-grad level. Want to know where the pipeline starts for that academic career. Example of a community member that hasn't completed high school, but being able to give some kind of recognition of prior learning that could lead to a TAFE course and creating pathways from the most community level. Hard to get funding for […] co-researchers previously because they weren't recognised as having formal qualifications. Start that pipeline earlier.
- 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.
- There was a tiny piece of this in a recent project ([…]) but I think that's a really strong principle for capacity building. We only know what we know and the work can become stronger when we are involved. It builds confidence for people.
- 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.

Key Point 4 – Culturally appropriate and respectful research practices are embedded, and clear benefits are identified

- Maybe uses some of the patterns of thought used by community, participation action research come[s] close to a traditional way of thinking about things – allows for collective thought. Not perfect, but empowering.
- My experience is that research is widely mistrusted, considering a long history of being the "subject" of research.
- Things are definitely improving but there is still so much work to be done to decolonise research practices.
- We really enjoy being involved in most Aboriginal-led research. It's inclusive and presents multiple benefits for our service and community.
- We need to turn it on its head and direct the research.
- I think that any researcher coming to remote communities should reside here and be required to meet local Elders, leaders and health staff.
- 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.
- 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.
- Remote experience. Has language/linguistic knowledge. Able to work with multi-cultural individuals as well.
- Trust is an issue, and my trust lies with our mob.
- Research is critical to improving outcomes that will in turn help Close the Gap.
- It's tiring working within institutional ways.
- A code of conduct for research institutions with mandatory requirements.
- The place of Elders in the conduct of research should not be underestimated, since they are the knowledge holders of their communities. Elders help ensure research is culturally appropriate, transparent, and most likely to benefit Aboriginal communities. Having Aboriginal people lead the research, whether as researchers or Elders, etc, would help ensure the project is culturally safe.
- Cut out the racist attitudes and make research more understood and therefore accessible.

- The […] report and guidelines to assist researchers in Aboriginal health is available on our website and outlines what is needed to do research well in Aboriginal communities. I think that Aboriginal community-controlled health services should have the right to be consulted on all health research in their region but not the right to veto. Ethics committees should require evidence that this consultation has occurred and whether a given research project has the support or not from the local ACCHS. […] has been seeking this in the national ethical guidelines for many years. There is no structure better than an ACCHS to give a strong Aboriginal community perspective on whether research will be of benefit or not in their community. There needs to be more infrastructure rounds from the MRFF so more ACCHS can employ research managers and other key positions so they can better engage with researchers in a manner which enables them to be in control.
- We appreciate being involved in research to benefit our community and other regions.
- I love research and reading research. I can spend hours and days reading on specific First Nation topics and for me it's useful because I am working towards the grant writing which leads to the possibility of receiving a grant and giving back to our mob.
- Feeding back outcomes.
- Allow mob to drive the [research] agenda.
- Our experiences have been very positive around research through the strong community-led design through the […] project at the […]. But we often get approached by researchers who are unknown to us and have no idea of community priorities or what we want out of research. These are the same researchers who are often very pushy and disregard our knowledge and expertise into research.
- Research must matter and be relevant, not alone to satisfy curiosity.
- Very overwhelming – often sign letters of support and never hear back – lots of work for our staff and no returns.
- Research benefit: – It depends how the researchers report on our community and […], and whether it's helpful or not. – […] has said yes to research where there is a feeling that it would be of benefit but it hasn't always been the case that the loop has been closed, researchers take data away and don't share it, or make assumptions about the data without involving […] during write-up. It gets muddy. – Project example: amazing outcomes out of a tiny project, shows what can happen when you work in a good way. – All research can be helpful to an extent, but the way in which the data and research is used can be harmful.
- We really enjoy being involved in most Aboriginal-led research. It's inclusive + presents multiple benefits for our service + community.
- There needs to be training for non-Indigenous researchers around Aboriginal and Torres Strait Islander-led research and the importance and necessity of things being done this way.
- Training and information sessions prior to commencement of any research.
- Basic cultural awareness + respectful ways of engaging would be good.
- Cultural training – Stakeholder engagement – Co-design training – Work with local people – Ensure the follow standard guidelines (they may need to be developed) before contacting ACCHOs.
- More training – culturally appropriate training, Aboriginal staff, RESPECT.
- Frequent training.
- Training and feeding back outcomes.
- That all researchers wanting to undertake research around Indigenous matters/issues undertake cultural awareness training/practice, including Indigenous researchers not from that particular tribal land. That researchers understand that they are not coming into the perfect research environment and that the capacity may have to be supported.
- Needs to be further education for our community and students to understand the difference between the Law and Lore.
- Training for staff to learn basic research.

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.
- 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.
- Knowledge translation: that's the point really. We would love to strengthen advocacy around core funding for primary health care and promotion. There is a team that works from a cycle of one project funding to another, it's good work that just gets slowly dispersed or lost. Good work doesn't get sustained. Within […], we work on cyclic funding, but always trying to think of ways that programs are sustainable should funding cease. We shouldn't have to do that, having policy and practice changes are welcomed. If research can make strong recommendations, then […] can take that to influence policy change and funding.
- Practice of converting research into policies.

ACCHS = Aboriginal Community Controlled Health Service; ACCHO = Aboriginal Community Controlled Health Organisation; ACCO = Aboriginal Community Controlled Organisation; AMS = Aboriginal Medical Service; NGO = Non-government organisation; MOU = Memorandum of Understanding; AHW/AHP = Aboriginal Health Worker; AHP = Aboriginal Health Practitioner; ATSI = Aboriginal and Torres Strait Islander; CEO = Chief Executive Officer; CQI = Continuous Quality Improvement; ORIC = Office of the Registrar of Indigenous Corporations; NAIDOC = National Aboriginal and Islander Day Observance Committee; MRFF = Medical Research Future Fund.

CONSolIDated critERia for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) statement

Governance
This research engages multiple levels of Aboriginal and Torres Strait Islander governance. Formal governance was enacted by the National Indigenous Health Leadership Alliance (NIHLA – formerly National Health Leadership Forum) which comprises of representatives from Aboriginal and Torres Strait Islander organisations and peak bodies committed to systemic and structural reform. The NIHLA has provided governance and oversight across all aspects of the research, guiding and strengthening the research by ensuring it is safe, impactful and upholds prioritisation of need and benefit for Aboriginal and Torres Strait Islander communities. The lead researcher (MK) met with the NIHLA at least bi-annually throughout the development, implementation, interpretation and dissemination of the research to ensure tangible and efficient practice and policy changes were made. The research, as led by a collective of Aboriginal and Torres Strait Islander researchers, uphold governance and oversight of all aspects of the work. All required ethical approvals were obtained, including from the Australian Institute of Aboriginal and Torres Strait Islander Studies (HREC reference no. EO323-20220414) and the Aboriginal Health & Medical Research Council (HREC reference no. 1924/22).
Prioritisation
This research emerged from the priorities of Aboriginal and Torres Strait Islander people and communities for truth telling and critical reflection of the field of ethics in health and medical research. As such, pre-existing, alongside new community partnerships have been established throughout the research to ensure the research continues to uphold the priorities and voice of Aboriginal and Torres Strait Islander people. The governance processes within this research ensure rapid translation of findings into policy and practice to meet the identified community priorities.
Relationships
This work upholds Aboriginal and Torres Strait Islander peoples rights to self-determination, leadership and decision-making throughout all stages of the research in line with the principles of the United Nations Declaration on the Rights of Indigenous People (UNDRIP) and ethical principles of Aboriginal and Torres Strait Islander health and medical research. Relationality to the work, communities and between the researchers has been pivotal to ensure the research safeguards Aboriginal and Torres Strait Islander people and communities throughout the development, implementation, interpretation and translation of this project. This responsibility and accountability to the improvement of health and wellbeing outcomes for Aboriginal and Torres Strait Islander people extends beyond the life of the project to ensure the researchers remained responsive to the evolving and changing needs and priorities of communities. Acknowledging that Aboriginal and Torres Strait Islander people are not homogenous and are a diverse people, the research team brought decades of experience and expertise across a range of settings and locations to ensure the research considered, and was appropriate, across and between communities and their contexts nationally.
Methodologies
This research has been led and implemented by Aboriginal and Torres Strait Islander experts and leaders across a range of disciplines in health and medical research. Indigenous worldviews and relationality, underpinned by Indigenist research methodologies ensure the research is transparent and accountable to

Aboriginal and Torres Strait Islander communities. As Aboriginal and Torres Strait Islander people and researchers, the concept of ethical practice is not new. The ways in which this research is conducted is deeply rooted in our lived experiences and realities, including the complexities of upholding relational research practices within Euro-Western systems. Consequently, this intrinsically influences how this research has been shaped, interpreted and translated, upholding Aboriginal and Torres Strait Islander rights to ethical research and outcomes.

Participation

This study sought to understand the experiences and perspectives of a diverse range of participants conducting health and medical research with Aboriginal and Torres Strait Islander people and their data. This included from Aboriginal and Torres Strait Islander communities, researchers and human research ethics committee members. The seeking of individual and community consent was imperative to mitigate burden placed on participants, particularly any Aboriginal and Torres Strait Islander people or communities. Indigenous data sovereignty principles were upheld to ensure the safety and security of all participants throughout the research. All data has been presented as deidentified to protect participants and communities.

Capacity

The *Murru Minya* project supports Aboriginal and Torres Strait Islander research capacity through the development and mentorship of an Aboriginal PhD Candidate and an Aboriginal community researcher. The guidance and leadership of the extensive Aboriginal and Torres Strait Islander research team has been woven throughout all stages of the research. Through respectful and reciprocal relationships, this research has engaged with key stakeholders within the Aboriginal and Torres Strait Islander community-controlled sector and other research institutes to build capacity within the sector across a range of areas including research design, implementation and knowledge translation.

Analysis and interpretation

Collaborative Yarning between the Aboriginal and Torres Strait Islander researchers was pivotal to the analysis process which prompted reflexive analysis and sense-making of the data. Drawing on our own lived experiences as described by Tuwahi-Smith, the research team have become deeply interconnected with the data as both the research*ed* and research*er*. Grounded in our standpoint, Nakata describes this *"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"*. Consequently, this uniquely influences and shapes the ways in which the data in this research have been analysed and interpreted. 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 whereby the predominantly non-Indigenous researchers and research systems are the subjects of Indigenous research as defined by us.

Dissemination

Rapid knowledge translation and dissemination of findings from this study have been interwoven and in-process prior to publication of this work. During project implementation, ongoing knowledge translation to project governance and leaders occurred, and a website was created with a focus on community-level translation in real-time. Through the website, members of the academic sector and community were able to register to receive regular newsletters and project updates. Prior to submitting manuscripts, in-process

findings of this study were shared with the research governing body and the Aboriginal Health & Medical Research Council Ethics Committee. A series of personal invitations, locally and nationally, were received to present to community organisations and research institutes. This has included presentations to the Wakul Yabung Aboriginal Health Research Panel at the University of Newcastle (NSW), Wardliparingga Aboriginal Health Equity Unit as the South Australian Health and Medical Research Institute (SA) and Telethon Kids Institute (WA). Key international presentations have included the Lowitja Institute International Indigenous Health Conference (2024), World Indigenous Cancer Conference (2024) and an International Knowledge Exchange Event held with Indigenous colleagues from the British Colombia Network Environment for Indigenous Health Research, Canada (2024). A 16-page knowledge translation booklet has been developed to share findings with key stakeholders and communities in the sector.