Including Indigenous knowledge in biomedical research: a co-autoethnography

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Summary

Background The need to improve biomedical research for the safe inclusion of Indigenous peoples is well documented. However, how one achieves this improvement, particularly in multisite, hospital-based research, is largely absent from the published literature. We aimed to conduct a reflexive dialogue to examine the challenges faced when adapting a hospital-based, biomedical acute rheumatic fever project in response to First Nations community feedback, thereby identifying possible areas for advancement in this type of research.

Methods This study used co-autoethnography, a qualitative methodology in which multiple researchers collaboratively reflect on and analyse their personal experiences related to a shared topic. We used this approach to reflect on the challenges of incorporating Indigenous knowledges into a biomedical acute rheumatic fever project, and to explore how the project itself evolved in response to feedback from First Nations stakeholders. Aboriginal coauthors used the First Nations' Yarning method to generate data for co-autoethnography until data saturation was reached (ie, once no new challenges were identified), at which point an all-author meeting led by an Aboriginal coauthor was held to present and further reflect on the tensions that had been encountered. Briefing and debriefing sessions between Aboriginal coauthors were held before and after the all-author meeting. The resulting data were additionally analysed through a collective writing process involving multiple revision cycles and further Yarning and discussions until every coauthor was satisfied that the findings were consistent with their ideas and experiences.

Findings 18 Yarns and meetings involving six researchers as participants were held between March, 2023, and November, 2024. Seven key challenges were encountered in honouring First Nations knowledge: barriers to community engagement; poorly suited project design; complications with biomedical funding structures; inappropriate research ethics documents; poor engagement with other biomedical research groups; the impact of the hospital setting on cultural safety; and anticipated disagreements and top-down team dynamics within the biomedical research team. We identified four major aspects of the acute rheumatic fever project that underwent adaptation in response to local First Nations stakeholder feedback: community consultation, project design, consent processes, and research team structure.

Interpretation In responding to First Nations knowledge and wisdoms, we were able to incorporate Indigenous ways of knowing, being, and doing into an acute rheumatic fever project while simultaneously retaining the biomedical conventions necessary for a robust scientific design. However, although we adapted the project (with difficulty), we do not recommend that researchers use the same process. Our adaptations to the ill-fitting biomedical research model placed unnecessary burden on First Nations stakeholders and created lengthy delays. Instead, we propose that biomedical research systems require remodelling and innovation to ensure fitness-for-purpose and safe expansion with First Nations peoples.

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Introduction

There are global concerns that biomedical research is being performed on Indigenous peoples rather than with, for, or by us.[1] Consequently, Indigenous peoples stipulate that community partnership and the inclusion of Indigenous knowledges in biomedical research are crucial.[1–3] However, such inclusion can prove challenging in inflexible institutional settings for three reasons. First, inequity has resulted in low numbers of Indigenous hospital staff and biomedical researchers, affecting research institutions' ability to provide culturally safe research. Second, prospective participants experiencing illness can come from numerous diverse communities with little notice, making meaningful engagement with each community near impossible. Third, biomedical research has been slow to engage with Indigenous knowledges and wisdoms.

In 2020, with little understanding of how these factors would affect our research, our then predominantly non-Indigenous biomedical research team began establishing a multisite, prospective observational study to investigate whether cardiac MRI can improve acute

Research in context

Evidence before this study

Research involving Indigenous peoples is widely recognised as requiring respectful, reciprocal partnerships between researchers and local communities to ensure culturally responsive practices that incorporate Indigenous ways of knowing, doing, and being. However, little is published on how to achieve this in multisite Indigenous-focused research conducted in institutional settings. We searched Ovid MEDLINE for papers published from database inception until Nov 15, 2024, with the search terms "Indigenous.mp" or "Aboriginal and Torres Strait Islander.mp" combined with the AND function and the search terms "institution", "tertiary hospital", "multi-site", "biomedical", "research", "co-design", "engagement", and "community". No restriction on language or year of publication was applied. A further search of references in the resulting papers and relevant government reports was also undertaken. Several papers discussed decolonising clinical care in tertiary services but did not touch on research. Some large-scale, multisite studies were identified; however, all were conducted from community-based primary health services. Several papers called for the inclusion of Indigenous knowledges into biomedical research, but no articles were found addressing how this inclusion could be achieved in institutional settings. In mainstream biomedical research, representation of Indigenous peoples in multisite studies was generally below population representation.

Added value of this study

This study builds on previous scholarship by Indigenous researchers, particularly the development of an Indigenous research paradigm: the framework of values, beliefs, and ideas within which Indigenous researchers have called for research to be conducted. This study aimed to contribute to improving health-care research equity for Indigenous peoples. As such, we provide a valuable real-world example of including aspects of an Indigenous research paradigm in a large-scale, multisite biomedical study on acute rheumatic fever conducted in hospital settings with First Nations Peoples. We describe the many challenges encountered while trying to maximise cultural safety for First Nations participants without compromising scientific merit or validity. This study highlights the importance of multilevel Indigenous leadership and provides a new model for Indigenous-focused biomedical research.

Implications of all the available evidence

Although many challenges arose during this research due to the clash between biomedical and Indigenous research paradigms, we were able to adapt the biomedical acute rheumatic fever study at the project level to incorporate elements of an Indigenous research paradigm. However, in the inflexible biomedical system, this adaptation resulted in substantial levels of community burden and extensive delays. Broad and innovative systems change is needed for this type of research to expand safely without burdening Indigenous communities and researchers. Inclusive research frameworks are crucial to ensuring Indigenous-focused research is conducted in a culturally responsive manner in the dominant system, while still investigating acute conditions and other health issues that are best studied in hospital settings. These frameworks could also be used in mainstream biomedical research to optimise cultural safety while ensuring that Indigenous representation is proportional to disease burden. Other communities and groups for whom biomedical research is poorly suited might also benefit from innovations to the biomedical model.

rheumatic fever diagnosis. Acute rheumatic fever is a generalised inflammatory illness that can occur following group A streptococcal infection.[4] As in many other colonised, high-income countries, acute rheumatic fever has been essentially eradicated in Australia's non-Indigenous population, but endemic rates continue in children and young people in numerous First Nations (ie, Aboriginal and Torres Strait Islander Peoples) communities,[5,6] predominantly in regional and remote areas.[7] The enduring effects of colonisation contribute to this imposed inequity,[8] with acute rheumatic fever rates increasing with socioeconomic disadvantage and poor access to health care (figure 1). The combination of these patient demographics and the locations of MRI scanners necessitates that the project, entitled Quantifying myocardial inflammation in acute rheumatic fever and rheumatic heart disease (I Heart MRI; figure 2; appendix p 2), be both First Nations focused and hospital based. Recruitment for the project started in April, 2023, and is currently approximately 30% complete.

See Online for appendix

Although we had not anticipated that the project would to be easy, we were nonetheless surprised at the numerous challenges we faced and the delays we encountered throughout the establishment of I Heart MRI. In the initial stages, we had little awareness of the clash of knowledge systems that our research existed within, described by Nakata as a "cultural interface".[9] This concept recognises that Indigenous and colonial knowledge systems exist and that these systems are so unalike that there is little to no commonality.[9] It contributes to why Indigenous involvement in colonially informed biomedical research is often fraught and why Indigenous scholars have long called for an Indigenous research paradigm to be recognised and used.[1,10] A research paradigm is the framework of values, beliefs, and ideas that guide how research is conducted, made up of: ontology (what we believe is reality); epistemology (how we think about that reality); methodology (how we go about discovering that reality); and axiology (our values and morals).[10]

Dominant in health-care research is the biomedical research paradigm, which is embedded in objectivism

(only one objective reality exists), sees knowledge as awaiting discovery, values positivism (ie, recognising only that which can be scientifically verified) and empiricism (ie, knowledge comes from experience and observation), operates within a rigid and narrowly defined framework,[11] and favours individualism.[12] In contrast, Indigenous research paradigms often value relationality and relational accountability,[10] are community based,[1,13] include local Indigenous knowledge systems,[14] involve Indigenous perspectives to choose methods and decide what knowledge is,[15,16] create emancipation and benefit for Indigenous peoples,[14] and challenge the dominance of colonial paradigms.[1,14,15] As such, biomedical and Indigenous research paradigms are very distinct and dissimilar. However, there is also a sociocultural–historical layer to this paradigmatic clash, as the biomedical research paradigm has been applied as a colonial tool of oppression.[17]

Historically, biomedical researchers created discredited and harmful racialised theories that supported the destruction of Indigenous peoples' lives and livelihoods via colonisation.[18] Considering these ideas something of an antiquated past is tempting; however, colonialism is always evolving,[19] and the past is inextricably linked to the present and the making of the future. For instance, researchers can study health inequities imposed on Indigenous peoples with little self-awareness of their own profession's complicity in causing these disparities in the first place. Similarly to the past, Indigenous peoples are still subtly blamed for health inequities and are consigned to being weaker or lesser than non-Indigenous people, particularly when the sociocultural–historical factors causing the inequities are ignored.[20]

Only through our work on I Heart MRI did our biomedical team members come to understand the ongoing legacy of this history and the existence of research paradigms outside of the biomedical system. Combined with meaningful community engagement, extensive feedback from project stakeholders, and the addition of more First Nations researchers to the team, the project has evolved substantially since 2020. We conducted this nested qualitative study with two aims: first, to reflect on the adaptations made to the I Heart MRI project and how these related to an Indigenous research paradigm; and second, to analyse the collective challenges faced throughout this process, with a focus on identifying opportunities for improvement and innovation in biomedical research.

Methods

Study design

This study used co-autoethnography, a collaborative qualitative method that positions researchers as participants and insiders with key knowledge, reflecting on interconnected or similar experiences to create a multivoiced narrative.[21] This method was chosen because it is relational and reflexive, and because it allows for

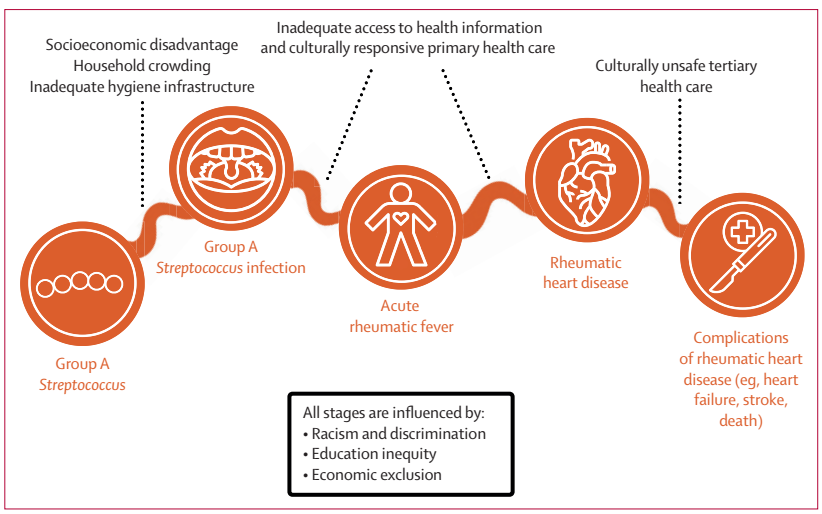

Figure 1: **Social determinants of health and progression to rheumatic heart disease**
The social determinants of health influence progression of Group A *Streptococcus* infection to rheumatic heart disease. Culturally responsive primary and tertiary health care are crucial in halting this progression.

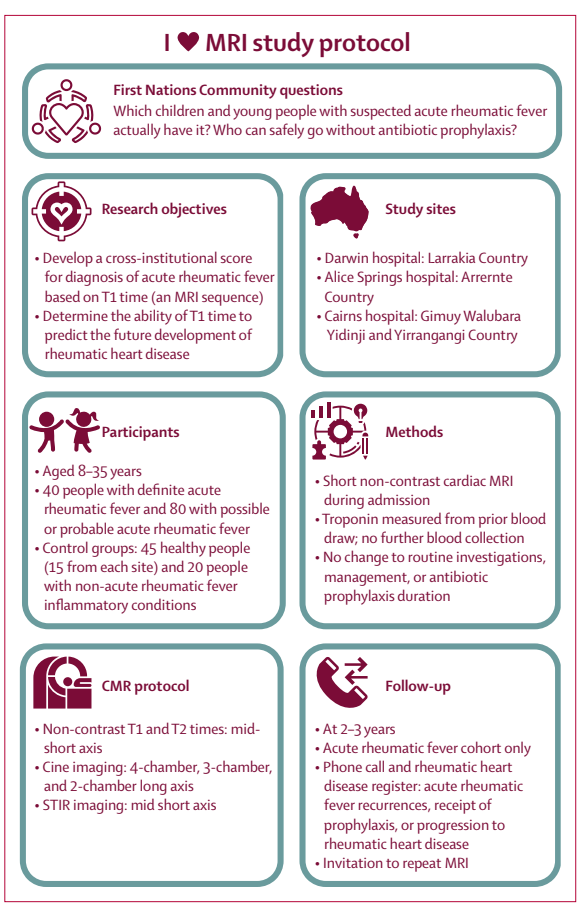

Figure 2: **Summary of the I Heart MRI study protocol**
CMR=cardiovascular magnetic resonance imaging. STIR=short tau inversion recovery. T1=longitudinal relaxation. T2=transverse relaxation.

storytelling and collective knowledge making. Although co-autoethnography is traditionally a written process, we also used spoken co-autoethnography to generate data, as it better aligns with the Yarning method, a First Nations, culturally specified communication process.[22] Yarning involves people coming together with a purpose and is relational.[23] It requires Aboriginal lived experience and is more than casual conversation: Yarning involves storytelling, deep listening, and relationship building.

***Panel 1*: Indigenous research paradigm principles used in this research**

- Honouring diversity and responding to local contexts[1,13,14]
- Privileging Indigenous perspectives[1,15]
- Indigenous control of research[1,14,16]
- Respect for Indigenous knowledge systems[10,16]
- Holism[1,10]
- Reciprocity[1,10]
- Respect and responsibility[10,15]
- Emancipation and tangible community benefit[14,15]
- Community partnership[1,13,15]
- Relational accountability[10,13,15]
- Reclaiming storytelling and oral traditions[13]
- Challenging the dominance of colonial paradigms[14,16]
- Addressing systemic racism in biomedical research[1,16]

Tacit and explicit experiences and memories that people have in common to inform relationality is important, as it will affect the data thickness (ie, how well the data captures the complexity of participants' experiences, contexts, and meanings) and quality.[22] Yarning creates knowledges underpinned by Indigenous worldviews and experiences, which cyclically allows for further expression of Indigenous knowledges. Researcher–participants were selected on the basis of extensive and long-term (ie, ≥18 months) involvement in I Heart MRI. This study is reported in line with the Standards for Reporting Qualitative Research (SRQR).[24] It is written from the perspective of Aboriginal authors to centre our ideas and reflections; however, all authors contributed to this reflexive dialogue.

Researcher positionality

JO'B is an Aboriginal woman from northwest New South Wales, a cardiologist trained in a traditional biomedical system with little experience in undertaking research with First Nations peoples before leading the I Heart MRI project for her PhD. KA is Wiradjuri and an experienced qualitative researcher who has worked as a nurse, health service manager, and educator in Aboriginal health in southeast Australia for more than 25 years. She became a co-supervisor of JO'B's PhD in 2023. TW is Gurang and has worked as an Aboriginal health practitioner for two decades across Queensland and the Northern

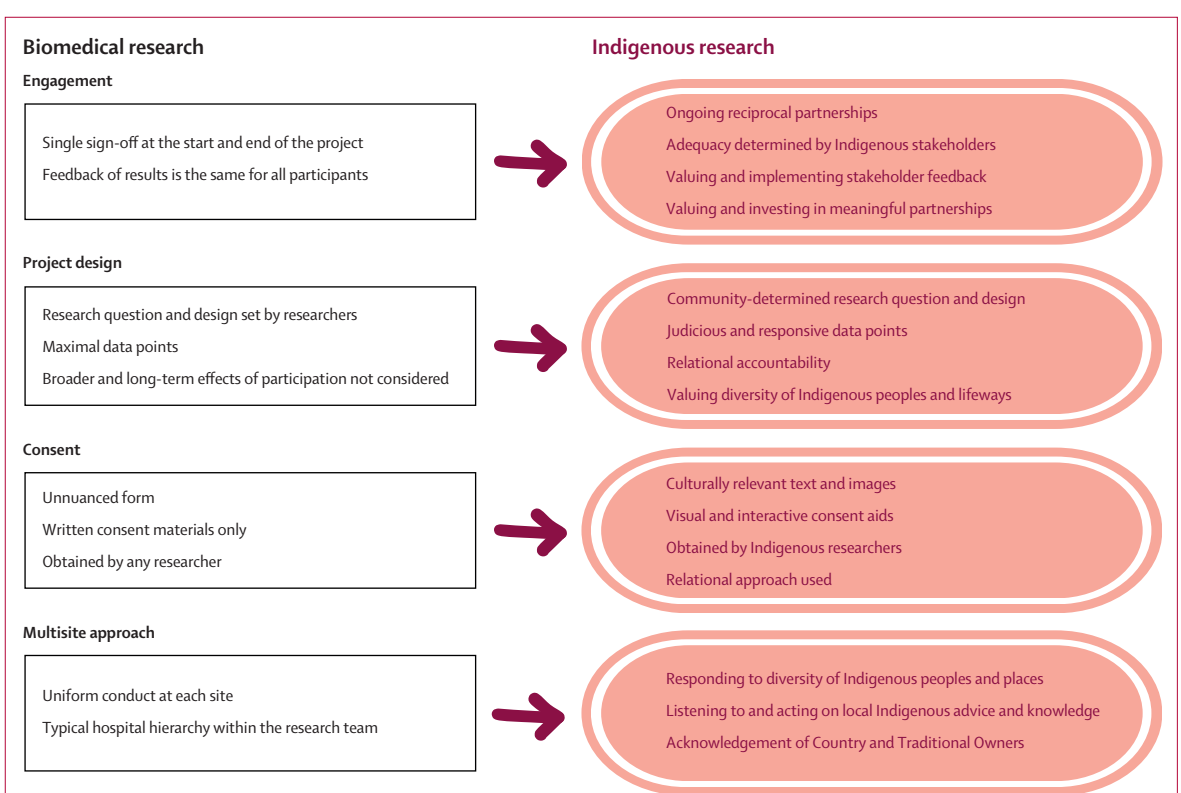

***Figure 3*: Biomedical to Indigenous research paradigm responsive adaptations**
Four major aspects of the I Heart MRI project underwent notable change to be more in keeping with an Indigenous research paradigm.

Territory. She is the I Heart MRI project coordinator at the Darwin site. VW is a senior Noongar woman, cardiac nurse, and qualitative researcher with decades of clinical and research experience in acute rheumatic fever and rheumatic heart disease. SJG is a non-Indigenous cardiologist and clinician researcher who has worked in First Nations health and research in both hospital and community-controlled health organisation settings for 15 years. She led the pilot study[25] that informed I Heart MRI and is a co-supervisor of JO'B's PhD. AJT is a non-Indigenous cardiologist and clinician researcher with expertise in cardiac MRI, who, prior to this body of work, had little experience in First Nations health research. He is the primary supervisor of JO'B's PhD.

Data collection

Initial Yarns were undertaken between JO'B and each Aboriginal coauthor (KA, TW, and VW) separately. The purpose was to reflect on the challenges encountered throughout the research process and how the project itself had been changed in response to First Nations stakeholder feedback (appendix p 22). Yarns ranged from 60 min to 90 min and some paired participants Yarned up to eight times. Recording the Yarns (both audio and video) at times felt intrusive, potentially stifling the flow of sensitive stories. In these instances, notes were taken by JO'B instead. JO'B also met with non-Indigenous coauthors (SJG and AJT) individually to discuss their experiences of the research before holding a biomedical author meeting (including JO'B, SJG, and AJT), which was both recorded and transcribed. Both in-person and online meetings occurred, in hospital, university, and outdoor settings.

Data saturation was considered to have occurred once no new challenges were identified. An all-author online meeting then took place and was both recorded and transcribed for convenience. In this meeting, challenges previously identified via Yarning were outlined by JO'B for further reflection. Cultural safety was optimised by

	Perceived research paradigm clash		Initial approach (biomedical)	Responsive adaptations (Indigenous)
	Biomedical research paradigm	Indigenous research paradigm		
Stakeholder engagement	The scientific aim is central, with engagement occurring at timepoints that meet researchers' needs	Engagement with community is central, reciprocal, and enduring, with the project progressing as determined by the community*††§	No codesign; anticipated that there will be a single sign-off at the start and end of the project (ie, the minimum required by ethics and governance); no relationality established at any site; uncertainty around who and how to engage; and feedback of results was planned to be uniform across sites, unchanged from methods used in mainstream biomedical research	Seeking out multilayered, local Indigenous perspectives, guided by hospital liaison officers; Aboriginal authors contacting every person, committee, and organisation suggested; Yarning with First Nations participants with acute rheumatic fever; actively responding to feedback received; engaging community-controlled health organisations and national stakeholder organisations via First Nations representatives early in the project to ensure prompt translation of results; collaborating with other research teams to minimise burdensome, repeated consent attempts; and results feedback will include site-specific, locally informed resources including flyers and videos to visually story the results
Project design	Project design focuses on researchers' needs to collect robust data, with broader and long-term effects of participation rarely considered	Project design is relationally responsive to local contexts and needs with an emphasis on participant and community experience*¶||**††	Research question and design set by senior non-Indigenous researchers before engagement (resulting in an ill-fitted design); collection of maximal data points, including echocardiography and repeat cardiac MRI for all participants (requiring a return to hospital) at 2 years of follow-up; and a choice of follow-up that was burdensome and dependent on being able to contact participants many years in the future	Protection (or creation) of a positive ongoing relationship with health care is prioritised; no use of needles (non-contrast cardiac MRI sequences only and troponin assay added to existing blood sample to avoid re-collection); use of a flexible follow-up period (2–3 years); research echocardiography abandoned and clinical echocardiography used to diagnose rheumatic heart disease; repeat cardiac MRI offered, but not universally performed; no drop-out label if an individual declines follow-up MRI; and state-based rheumatic heart disease registers used for follow-up when participants are not contactable (consent obtained for this approach)
Consent	Consent focuses on achieving written individual consent and is minimally relational	Relationality in consent is highly valued to ensure trust in researchers; knowledge transfer via non-written methods is often preferred‡†††‡‡	Use of an unnuanced written consent form only; any researcher can obtain consent	Consent obtained by a First Nations researcher when possible; Yarning and establishing relationality before project discussion; unbiased support from First Nations liaison officers, health workers, or interpreters offered to all participants; involvement of other family or community members encouraged; storying the research in addition to the use of a written consent form (ie, inclusion of a video of an Aboriginal child having a cardiac MRI, site-specific photos of the scanner, project artwork, and an interactive toy MRI scanner); and obtaining consent not attempted if family feel overwhelmed, or if an interpreter is required but is unavailable
Multisite approach	The project is conducted in a uniform manner at each site with consistent research team structure and hierarchy	The diversity of Indigenous countries and peoples are honoured at each site, leading to substantial variation in how the research is conducted¶||§§	The approach used at the Darwin and Cairns sites was unchanged from the one used in Alice Springs for the pilot study	Use of site-specific project conduct, team structure, recruitment, and follow-up processes that continuously evolve in response to local First Nations feedback; use of a consistent cardiac MRI protocol and data collection points to maintain project validity; following a collaborative, non-hierarchical team approach that privileges First Nations perspectives (with local perspectives privileged over non-local ones); and use of site-specific resources (eg, activity books for paediatric participants and photos of MRI scanners and staff)

Footnotes indicate the relevant Indigenous research paradigm principles. *Community partnership. †Indigenous control of research. ‡Relational accountability. §Reciprocity. ¶Honouring diversity and responding to local contexts. ||Privileging Indigenous perspectives. **Holism. ††Respect and responsibility. ‡‡Reclaiming storytelling and oral traditions. §§Indigenous control of research.

Table: **Responsive adaptations of the I Heart MRI project and their relation to an Indigenous research paradigm**

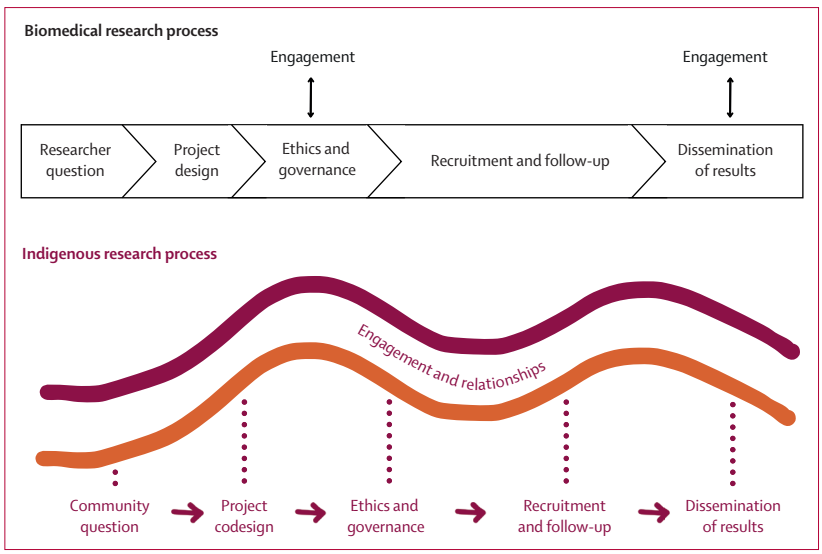

Figure 4: **Biomedical and Indigenous research processes**
In a biomedical paradigm, the project is central, with engagement occurring at timepoints that meet the researchers' needs. In an Indigenous paradigm, engagement is central, meaningful, and enduring, with the project progressing as determined by the community.

having an Aboriginal researcher–participant (JO'B) lead the meeting, privileging local (TW [who recruits participants at the Darwin hospital site]) then non-local (VW, KA, and JO'B) Aboriginal perspectives, and having briefing sessions between JO'B and each coauthor before the meeting. These sessions allowed for input from the Aboriginal coauthors on how the all-author meeting should be conducted. Debriefing sessions between JO'B and each Aboriginal coauthor occurred after the all-author meeting.

Data analysis

Following the co-autoethnography method,[26] JO'B read and reread the transcripts and Yarning notes, writing down reflections and thoughts as part of the review. This work was followed by categorising data and identifying patterns to group data. These groupings formed stories of the collective challenges faced throughout the research process and how these challenges were overcome, with a focus on the institutional factors influencing these experiences. A collaborative writing process followed to refine the stories presented and further discussions were undertaken when clarification of specific points was required. Multiple review cycles were needed until every coauthor was satisfied that the findings were consistent with their ideas and experiences.

A similar process was used to identify and analyse specific project components that were adapted in response to First Nations feedback. Notes and transcripts were reviewed by JO'B to form a list of all the project changes that had been made, before grouping these changes into larger categories. JO'B and KA then reflected on how the problematic initial project approach related to a biomedical research paradigm before linking the adaptations of the project components to the principles of an Indigenous research paradigm (see panel 1). These links were similarly refined by JO'B and KA through a collaborative writing process involving several revision cycles.

Role of the funding source

The funders of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

Results

In total, 18 Yarns and meetings with six researchers as participants were held between March, 2023, and November, 2024. Seven key challenges arose in honouring First Nations knowledge. The story of each challenge is outlined below, followed by how it was overcome at the project level. These challenges subsequently informed four focal project adaptations to honour First Nations stakeholder feedback (figure 3). Specific examples of the changes made and how these changes relate to the paradigm clash are described in the table. Broader issues that had been encountered while undertaking biomedical research with Indigenous peoples are outlined in the appendix (p 23).

The first key challenge involved barriers around meaningful First Nations engagement for research in the hospital setting. This challenge was particularly driven by an inability to predict which numerous and diverse communities prospective participants would come from. Burdening First Nations hospital staff with further workload and engagement attempts felt inappropriate. The staff were few and busy, and their primary focus and expertise was on cultural safety and patient care, not biomedical research. Therefore, communication via email seemed the easiest way to gain First Nations staff support for the project, and ethics approval was initially granted on the basis of this support alone. However, this superficial engagement resulted in an ill-fitted project design, unsuited consent processes, and difficulty employing local research staff.

To remedy this challenge, JO'B met with Aboriginal and Torres Strait Islander hospital liaison officers in person and identified herself as an Aboriginal researcher. Over several meetings, relationships developed via researcher accountability and shared motivations. The hospital liaison officers then shared their expertise on local mobs (ie, groups of First Nations peoples) with JO'B and recommended stakeholders for engagement. The hospital liaison officers, with their existing relationality with the stakeholders, then introduced JO'B as an Aboriginal researcher. This facilitated introduction increased project interest and created further crucial stakeholder referral. However, stakeholders shared their expertise as an unpaid cultural load on top of their already busy lives. JO'B noted: "what I have done is not the right thing: [First Nations] people have given me their time, donated their

time and effort because I'm Aboriginal and they want to help me. That's not a feasible ongoing model." To somewhat recompense these stakeholders, belated reciprocal activities are being undertaken, predominantly by JO'B and TW, by providing clinical education sessions with both hospital and community-based First Nations health teams and participating in First Nations advisory groups for clinical and research projects. In this way, a shift to a more relational research model began (figure 4).

The second challenge that emerged was the incompatible project design. As JO'B engaged with further stakeholders at research sites, including young people with acute rheumatic fever and their families, the unsuitable design became apparent. Stakeholders explained that the numerous data points and rigorous follow-up were impractical (appendix p 22). Therefore, JO'B, local acute rheumatic fever clinicians, and MRI departments worked on feasible compromises, which JO'B took back to the biomedical research team members for consideration of their impact on result validity. The updated design was then approved by local First Nations stakeholders before ethical and governance amendment submissions were made. The same circular process of responsive adaptation is being used as stakeholder feedback continues to be received. As JO'B noted, "Receiving feedback (from stakeholders) was not a passive process: I had to actively create that space, be humble, listen, show respect... discuss how that feedback would be used and be accountable: update stakeholders showing how their advice was implemented." Although amendment requests have never been declined, these inflexible institutional processes are messy and time consuming; the current protocol version is version 6, and the project duration is anticipated to be 3 years longer than originally planned. JO'B noted that "it takes a while for everything to go through and then I worry that it looks like we're not doing it [implementing the feedback]... but actually we're just waiting for 'official' approval to enact the feedback".

The third challenge proved to be biomedical funding structures. Initial timelines were unrealistic due to AJT, SJG, and JO'B's limited experience in Indigenous-focused research. To overcome this challenge, extensions were sought and approved by the funding bodies, allowing for completion of one project component. Further funding is required to complete a second component. Initial codesign would have mitigated the stakeholder burden and project delay. However, due to the detail required for funding applications for expensive MRI research, initial codesign would have created a substantial unpaid cultural load for the local community if the bid had been unsuccessful. Unpaid contributions by researchers are typically built into professional pay structures. However, First Nations employees are often approached for multiple episodes of unpaid advice, consultation, and teaching on top of their usual workloads. KA noted: "there isn't anybody employed to do the co-design with the researchers... so they'll come to other people like a HLO [hospital liaison officer] who is not employed to do that... and so it's like there's a missing workforce". In the I Heart MRI project, we imposed further unpaid burden when adapting the project as we did not allocate funds for local First Nations input and expertise in our funding applications.

The fourth challenge was that available templates of research ethics documents relied on written traditions that favoured English. We were aware that some potential participants might value oral knowledge production traditions and speak First Nations languages. TW noted that "every single family is different, every single presentation is from a different group of people and tribes and customs and languages". We assumed that verbal consent was unlikely to be approved institutionally and, most importantly, none of the stakeholders requested it. Instead, hospital liaison officers recommended visual and audio methods, such as video storying, to explain the project. In addition, Aboriginal artwork was commissioned for the consent forms to build a sense of interest and relevance (figure 5). When

Figure 5: **Artwork titled Journey of Healing by Chloe Jones**
The main element used in this piece is water. Water is considered a healing agent in many Aboriginal cultures. Water gives life and heals life. The water feature in this piece is in the centre, showing the connection of waterholes through waterways and rivers. The meeting grounds symbolise the merging of our communities to support and heal together. The animal tracks signify the journey of healing by showing a journey along the river. The contrast of the warm and cool colours is also used to show the process of healing. The lined pattern on the edging and the centre represents running water, which in turn signifies a journey.

possible, consent was (and continues to be) obtained by First Nations project staff.

The fifth challenge was biomedical engagement. Clinician interest assured us the project had merit, but before obtaining funding, engaging some of the biomedical research groups working in the field of acute rheumatic fever was challenging. Although they were supportive of the project concept, few had the capacity to contribute. Understandable wariness of a predominantly non-Indigenous remote research group with little experience in acute rheumatic fever probably contributed to this challenge. Having our team spend more time at the research sites might have mitigated this wariness; however, collaboration was eventually developed via First Nations networks. Employing relationality, JO'B was reintroduced to other biomedical research teams by senior Aboriginal stakeholders, with subsequent acceptance and support.

The sixth challenge was using hospitals as the setting for Indigenous research. Hospitals are often contested sites for First Nations peoples who can associate hospitals with trauma, cultural insensitivity, disempowerment, sorry business (ie, a time of mourning in the community), and child removal. The extent of this association was not fully understood by AJT and SJG, and with MRI scanners located predominantly in hospitals, there was no alternative setting in which to conduct the I Heart MRI project. As community engagement progressed and recruitment began, the impact of the hospital setting became clearer. At times, JO'B grappled with whether continuing the project was justified: "because of racism, and the admissions are so hurried, I still go back and forth about whether this is the right thing to do. You know, hospitals aren't great places, they're not safe places. Should we even be doing this? Do you ever think that?" Feelings of overwhelm, communication barriers, systemic racism, and mistrust were more common than we had anticipated. Furthermore, the fast-paced nature of hospital care, driven by short-term goals such as discharge, limits the inclusion of Indigenous research paradigm elements, such as building trusting relationships, having lengthy Yarns to obtain consent, and involving multiple family and community members in decision making (table). Several MRI scans were cancelled due to busy MRI departments that appropriately prioritised clinical imaging. Therefore, recruitment attempts have been adapted to occur only once MRI availability is confirmed and when the anticipated admission length is sufficient for consent and scanning. This approach reduces participant eligibility and prolongs timelines but lessens the negative effects of participation. Employing local First Nations research staff proved crucial to overcoming some of the institutional limitations. Local understanding of languages, cultural protocols, and body language informs which families are appropriate to approach for recruitment and are comfortable giving informed consent. Most importantly, employing local First Nations staff diminishes power imbalances, meaning conditions are optimised for families to feel safe in declining participation. As TW noted: "If we give up and say we won't do research in hospitals at all, we're letting them control us more."

However, community expectations of Aboriginal team members have understandably been higher, and these team members are responsible to the community in ways that AJT and SJG are not. This relational accountability has benefited the project, but at an individual level, every delay and negative participant experience has weighed heavily on Aboriginal team members as our social and cultural responsibilities are overlaid with this research work. This weight is especially felt by local First Nations staff. TW noted: "It's just different for us, we're held to a different standard. I've gotta worry about my reputation... I have a set of rules and my culture that I have to be mindful of."

The final challenge was anticipated biomedical disagreement with implementing stakeholder feedback. JO'B anticipated conflict within the research team regarding flexible follow-up, additions to consent processes, and reduced data collection. At times, this concern created substantial anxiety. However, these tensions never arose due to SJG and AJT listening carefully and being reflexive. JO'B noted: "I reflected on it and I don't think a single thing I suggested, Andrew said no to. Not anything... He didn't speak out of turn, he said yes to everything." KA noted: "He's clearly like 'there's something here I don't understand but I understand enough to know something has happened'." As relationality and trust deepened, the initial hierarchical team structure and biomedical top-down approach

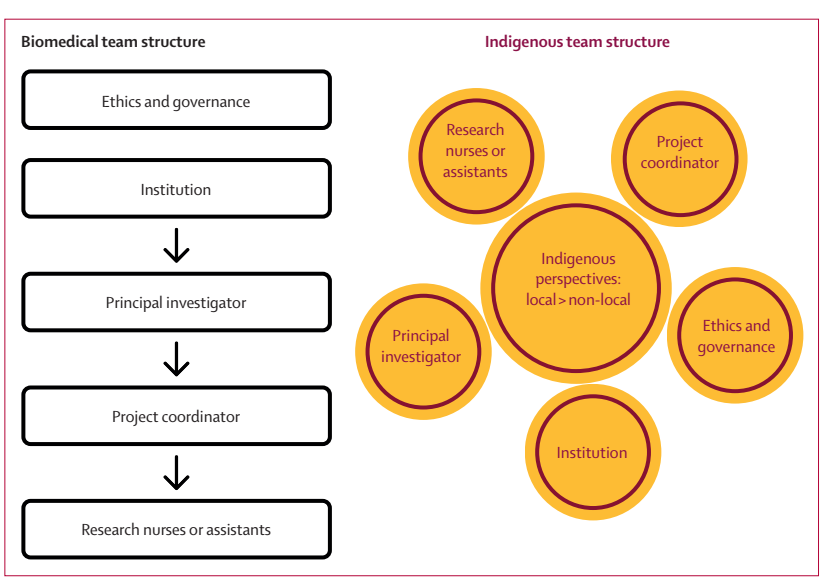

Figure 6: **Biomedical and Indigenous team structures**
The biomedical research team structure is typically hierarchical, whereas an Indigenous research team privileges Indigenous perspectives (particularly local ones), regardless of the individual's position or role.

moved more toward centring local First Nations knowledge and perspectives (figure 6).

Discussion

In this qualitative study, we applied Yarning and co-autoethnography to reflect on the challenges encountered when incorporating Indigenous ways of knowing, being, and doing into a multisite, tertiary health-care study. Our findings show that overcoming these challenges at the project level, although possible, created a substantial community burden and lengthy delays. Broader biomedical research remodelling and innovation is required to ensure fitness for purpose and safe expansion with Indigenous peoples (panel 2).

Many of the challenges the project encountered occurred due to biomedical researchers being underprepared to conduct research with First Nations peoples. Medical and research training rarely educate on research paradigms beyond the dominant biomedical paradigm, contributing to biomedical researchers struggling to work in Indigenous contexts[27] and assuming that Indigenous peoples inherently know how to conduct Indigenous research. Leaving the Indigenous aspects of a project for only Indigenous researchers to address can result in these researchers feeling unsupported and potentially leaving research altogether.[28] Collaborative approaches that elevate Indigenous perspectives are imperative. Substandard training might lead to biomedical indoctrination, as experienced by JO'B, or leave Indigenous researchers unable to navigate either paradigm comfortably.[29] Decolonising practice and unlearning biomedical normative frameworks continue to be active processes for JO'B, even as an Aboriginal person. Improvement requires biomedical researchers to be accountable: to learn about the colonial history of biomedicine; practice cultural humility;[30] employ reflexivity in their daily practice;[13] and use open-minded and responsive approaches to safely include Indigenous peoples in their research.

Gatekeeping within Indigenous-focused research fields such as rheumatic fever can create barriers to new researchers and projects that are aligned with community priorities. The so-called publications-as-currency nature of research can mean that if coauthorship is not assured, contributions can be difficult to justify for researchers with time constraints. However, this system hampers the truly collaborative work required to solve complex issues, minimise the community burden of endless individual consultation attempts, and ensure that all potential innovative solutions are optimised before being brought by a known, trusted, diverse, and experienced team to a community for subsequent codesign (if there is community interest). Communities, not researchers, should decide which projects are undertaken. The scarcity of First Nations biomedical researchers means we are particularly vulnerable to gatekeeping.

For I Heart MRI, the single most important project factor for community and biomedical engagement has been First Nations leadership. Non-Indigenous researchers cannot replicate what an Indigenous researcher can bring to a project due to different worldviews and perspectives.[10] Similarly, non-local Indigenous researchers cannot bring the same insights that local Indigenous researchers can. Capability building to move Indigenous researchers from solely participant-facing roles to leadership positions is crucial to progress biomedical research with Indigenous peoples. Notably, numerous families identified our project's Aboriginal leadership as a motivating factor in their participation.

We made many errors when establishing I Heart MRI and expect further (and ongoing) evolution of the project as stakeholder feedback continues to be received and implemented. Whether adaptations have resulted in culturally safe research remains uncertain; a qualitative

***Panel 2*: Recommendations for institutional changes and how these changes relate to the principles of an Indigenous research paradigm**

- Institutional commitments to providing mandatory, widespread, and effective anti-racist training of clinical and research staff to ensure cultural safety across all care*†
- Broad biomedical research education to include other paradigms and to teach the colonial history of the dominant health-care system‡§
- Flexible ethics and governance frameworks that encourage fluid and ongoing incorporation of stakeholder feedback¶||**
- Engagement grants to allow for:
  - Adequate time for meaningful, respectful relationships to develop††‡‡
  - Renumerated codesign of projects‡¶**
  - Provision of community-selected benefits that persist regardless of project outcome (such as health promotion materials or service delivery by clinician researchers)†§§¶¶
- Updated biomedical funding assessment frameworks and diverse assessor teams to ensure progressive projects that incorporate Indigenous ways are recognised and rewarded‡||
- Funding models that support flexible timelines to:
  - Encourage enduring engagement††‡‡
  - Avoid rushed or coerced recruitment†‡‡
  - Ensure projects are completed with definitive result†¶¶
- Place-based Indigenous hospital research liaison services to:
  - Ensure protected and paid time for consultation†¶
  - Provide realistic assessment of project feasibility¶¶¶
  - Support clinical liaison services‡‡§§
  - Provide traineeship opportunities**¶¶
  - Streamline consent processes (eg, hospital research liaison officers representing multiple projects could meet with potential participants and establish which project, if any, best fits the family's health priorities)‡‡||||
  - Streamline communication with community-controlled health organisations for feedback and implementation of results†¶**¶¶
- Consideration of non-written consent options for health-care research if these are identified by local stakeholders as appropriate¶***

*Addressing systemic racism in biomedical research. †Respect and responsibility. ‡Respect for Indigenous knowledge systems. §Challenging the dominance of colonial paradigms. ¶Honouring diversity and responding to local contexts. ||Privileging Indigenous perspectives. **Indigenous control of research. ††Community partnership. ‡‡Relational accountability. §§Reciprocity. ¶¶Emancipation and tangible community benefit. ||||Holism. ***Reclaiming storytelling and oral traditions.

study is underway to assess this outcome, as only participants can decide whether it was achieved. Providing culturally safe clinical care is paramount; without it, biomedical research with Indigenous peoples will never be able to safely expand. And although this expansion is our eventual goal, we recognise that much change (at both researcher and systems levels) is required for it to occur in a culturally appropriate way.

Overall, I Heart MRI continues to operate within a biomedical research paradigm (the project seeks a single truth that can be objectively and robustly measured by science), as is necessary for quantitative health-care research aiming to influence clinical practice. However, the project now includes many principles of an Indigenous research paradigm (table). This new model did not occur intentionally as a research exercise, but rather organically as First Nations feedback was iteratively implemented and biomedical researchers (JO'B, SJG, and AJT) listened and learned.

Our co-autoethnographic approach had several limitations. Yarns were not recorded, so errors are possible. However, Yarn repetition and the researcher–participant format allowed multiple opportunities for corrections and additions. Having only one all-author meeting potentially reduced data richness, hence the inclusion of the Yarning data. These reflections are our own and might not represent the wider community or other researchers. Given our ongoing work on I Heart MRI, we have a vested interest in reporting its progress favourably. Some sensitive events that were difficult to navigate were not shared in the all-author meeting and this Article. This exclusion is a reality of respecting peoples' stories. Future applications of the method could be enhanced by increasing participation by local First Nations stakeholders, including team members from all project sites, and hosting multiple all-author meetings to strengthen relationality.

In conclusion, there is an urgent imperative to transform biomedical research for the safe inclusion of Indigenous peoples. We were able to overcome the challenges that arose at the project level and include elements of an Indigenous research paradigm in the I Heart MRI project; however, this work was impeded by the project's inflexible institutional setting and processes. Systemic changes such as updated funding models, flexible ethics and governance processes, hospital research liaison services, and improved biomedical research education are required to achieve equity in biomedical research in a way that elevates Indigenous voices without burden.

Contributors

JO'B and KA contributed to the overall study concept and design. All authors were involved in the data collection, analysis, and interpretation. All authors provided critical intellectual input and reviewed and edited the manuscript. SJG and KA accessed and verified the data. All authors reviewed and approved the final version of the manuscript. All authors had full access to all data in the study and had final responsibility for the decision to submit for publication.

Declaration of interests

We declare no competing interests.

Data sharing

Our Yarning was personal and often involved sensitive and confidential events so sharing of Yarning notes and meeting transcripts is not permitted. However, a summary can be provided on reasonable request to the corresponding author.

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