Indigenous people's perspectives on sharing health data for service delivery purposes: an inquiry using Indigenous methodologies

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Summary

Background With healthcare's accelerating digital transformation and expanding data-sharing capabilities, it is essential to uphold Indigenous Data Sovereignty (IDSov)—which affirms Indigenous ownership and authority over health data relating to Indigenous communities. Indigenous Data Governance (IDGov) provides the mechanisms through which IDSov is enacted, ensuring Indigenous Peoples lead decisions about how data are collected, accessed, and used. Our research investigates a local enactment of IDGov, discussing how custodial stewardship is enacted in data-sharing arrangements between an Aboriginal and Torres Strait Islander community-controlled health organisation and a government birthing facility. The research aimed to understand Aboriginal and Torres Strait Islander service users' and health workers' perspectives on how/whether to share data between services.

Methods Led by a community-controlled organisation, the study used Indigenous methodologies, including 'yarning'—a traditional knowledge-sharing practice. An Aboriginal researcher conducted yarns with Aboriginal and/or Torres Strait Islander staff and perinatal service users. Collaborative analysis was undertaken using an adapted 'Thought Ritual', an Indigenous analytical framework.

Findings Analysis identified four domains: 1) Power and Control in Data Sharing—Data sharing can shift power dynamics, affecting sovereignty and community control, 2) Safety Concerns—Participants cited legal, cultural, and psychosocial risks tied to stigma and systemic racism, 3) Ability to Do My Job—Limited data access can hinder effective service delivery, and 4) Not Everything Should Be Shared—There is a clear preference for consent-based, selective data sharing.

Interpretation Honouring Indigenous perspectives in data-sharing arrangements is an ethical obligation. In perinatal settings, upholding custodial stewardship helps safeguard sovereignty, safety, and equitable outcomes.

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Keywords: Indigenous; First nations; Digital data sharing; Indigenous methodologies; Maternal health; Decolonisation; Routinely collected health data

Introduction

We begin this paper 'Propa way' with the Aboriginal and Torres Strait Islander protocol of acknowledging Country. We acknowledge the Goorie Nations as the traditional owners of the unceded lands this research was conducted on and pay our respects to their ancestors and descendants. This research is grounded in local Aboriginal terms of reference shared by community

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Research in context

Evidence before this study

Previous research has called for Indigenous control over health data, but few studies have explored how data governance is enacted in real-world service partnerships, especially in perinatal care.

Added value of this study

This study provides empirical insights into how custodial stewardship can support ethical data sharing, highlighting Indigenous People's perspectives on sovereignty, safety, and selective sharing.

Implications of all the available evidence

Upholding Indigenous Data Sovereignty requires local community-led governance, relational accountability, and infrastructure that supports reciprocal, culturally safe data-sharing practices.

Elders and actualised through the Cultural Integrity Investment Framework of the Institute for Urban Indigenous Health.[1]

This paper focusses on data sharing as one mechanism through which the health information of Indigenous Peoples is shared—and raises discussions around how to appropriately enact this sharing in ways that uphold, rather than compromise, Indigenous self-determination and governance. The integration of electronic health records, telemedicine, and big data analytics in healthcare has potential to enhance service delivery, client engagement, and health outcomes. In the rapidly evolving digital landscape, healthcare data is increasingly connected, shared and aggregated, promising improved service delivery, personalised care, and enhanced research capabilities.[2] However, the implementation of these technologies will not serve Indigenous communities if they do not adequately consider, using Indigenous terms of reference, the diverse contexts and priorities of Indigenous communities.[3–5] Across many countries, Indigenous Peoples continue to experience systemic healthcare inequities due to colonialism, historical trauma, and ongoing marginalisation.[6] Colonising practices displace and separate Indigenous Peoples from their culture, land and resources, fundamentally shaping socio-economic status,[7] access to healthcare and health outcomes.[8] As Czyzewski[9] asserts, colonisation is not a 'finished project' (p. 10) but an enduring determinant of health.

The realities of colonisation necessitate a thoughtful approach to healthcare data management,[10,11] particularly when data is used outside Indigenous-led organisations.[11,12] The concept of Indigenous Data Sovereignty (IDSov) can be helpful, and is defined in Australia as the right of Indigenous Peoples to exercise ownership over Indigenous data—expressed through the creation, collection, access, analysis, interpretation, management, dissemination, and reuse of that data.[13,14] Indigenous data "refers to information or knowledge, in any format or medium, which is about and may affect Indigenous peoples both collectively and individually"([14], p1). To enact IDSov, effective data practices must embed Indigenous Governance, recognising the authority of Indigenous communities to lead decision-making across all aspects of life.[14–16] This broader governance provides the foundation for what is frequently termed Indigenous Data Governance (IDGov), which refers to efforts to ensure that data practices reflect Indigenous values, priorities, and ways of knowing.[13,14]

Locally in SouthEast Queensland where this project was conducted, there is growing community discomfort with the terms *IDSov* and *IDGov*, which are increasingly seen as co-opted by colonial institutions such as universities and government agencies. While the intent behind these terms may align with local ways of doing things, their appropriation and misuse have rendered them less appropriate for our context. Instead, we have used term 'custodial stewardship', which resonates more strongly with local terminology and lived experiences of community in relation to enacting our ethical obligations to community.[17] While distinct in language, custodial stewardship is situated within an IDGov framework and supports ethical, respectful, and self-determined data management practices.

Custodial stewardship

We use the term custodial stewardship to reflect the sense of profound obligation to protect and manage knowledge, land, and resources for future generations held by local Aboriginal peoples.[17] Unlike Western notions of ownership, this obligation emphasises collective governance, intergenerational responsibility, and reciprocity.[1,18] The concept of custodial stewardship is (re)emerging internationally in environmental management, where Indigenous communities apply Traditional Knowledge systems to steward land, water, and skies (e.g.,[19]). Similarly, in health data management, custodial stewardship can be considered a mechanism to support Indigenous communities retaining control over their data, aligning collection, storage, and use with cultural values and priorities. Custodial stewardship involves "significant responsibility for chartering the data along its intended path, with its intended spirit and within its intended place" ([3], p.5).

Western frameworks often use concepts such as 'social licencing' to describe informal, ongoing community acceptance of projects or research.[20] Such concepts operate within Western paradigms, often relying on trust-building with Indigenous communities while maintaining institutional authority.[20] In contrast, custodial stewardship embeds Indigenous epistemologies into governance structures and proactively integrates Indigenous leadership and decision-making, positioning Indigenous Peoples as authoritative stewards rather than passive stakeholders.[3] This distinction is crucial in health data governance, where trust established by Western approaches such as social licencing may be exploited for purposes misaligned with Indigenous priorities. Beyond legal and institutional requirements, embedding custodial stewardship of Indigenous health data is an ethical obligation which enacts Indigenous Governance, self-determination, and relational accountability as data moves through healthcare systems.

Indigenous health data sharing

There are recognised benefits to sharing health data, but also significant risks, especially in Indigenous contexts.[4,5]

Benefits include that data sharing can facilitate personalised treatment based on aggregated health data, enabling healthcare providers to address the specific needs of Indigenous populations.[21] Access to comprehensive health data can also inform public health initiatives, leading to targeted interventions that address prevalent health issues in Indigenous communities, such as diabetes and cardiovascular disease.[22] Further, data sharing can enhance IDSov if arrangements ensure leadership by Indigenous communities, supporting stewardship of health data and agency in health decision-making.[16] Such Indigenous control of health data strengthens its relevance[23] and increases the likelihood of funding and resources for programs that benefit Indigenous communities.[24] Another potential benefit of data sharing is that it can encourage collaboration among health and social care providers and community leaders, fostering a holistic approach to health that can respect Indigenous cultural practices.[25] Indigenous-led health service partnerships provide innovative models of interprofessional collaboration (e.g., flattened hierarchies, health justice partnerships or including traditional healing within clinical care), which have been shown to improve holistic health outcomes, increase preventive care uptake, and improve engagement from Indigenous communities.[25]

However, there are significant risks of data sharing in Indigenous contexts. The potential for data to be misused by external entities raises serious concerns about privacy violations and exploitation.[26,27] Indigenous communities have historically experienced invasive data collection and misuse of their information (such as using biological samples or stories without consent), leading to justifiable wariness.[16] Inadequate protections for data privacy and cultural integrity may erode trust between Indigenous communities and (Indigenous and/or non-Indigenous) healthcare providers, researchers and/or institutions.[4] Sharing health data without proper safeguards can perpetuate processes of colonisation and result in loss of autonomy over health information.[5] Further, the use of Indigenous people's health data without proper consent or cultural understanding can lead to appropriation and misrepresentation of Indigenous knowledge.[26] Extracting data or findings from Indigenous communities and presenting them out of context, or without honouring the voices and stories of the community, is a form of cultural misappropriation. Such practices violate Indigenous Cultural and Intellectual Property rights.[28]

Although the risks and benefits of digitising and sharing data have been explored in academic literature, including by Indigenous scholars (e.g.,[3,4,12]), to our knowledge there is limited/no empirical research exploring the perspectives of Indigenous health workers directly involved in healthcare delivery or those accessing healthcare services.[29] This manuscript specifically seeks to understand the perspectives of Aboriginal and/or Torres Strait Islander health workers and people accessing care within these services on data sharing. Custodial stewardship of Indigenous health data is complex and requires locally informed, culturally nuanced approaches. The stakes are high: without locally appropriate IDGov mechanisms such as custodial stewardship, there is a risk of unsanctioned data sharing, leading to social and moral harms for Indigenous Peoples and a potential breakdown of data-driven initiatives aimed at improving health outcomes.[14]

This study addresses these concerns by exploring the research question: How do Aboriginal and/or Torres Strait Islander staff and people accessing community-controlled health services view the data-sharing arrangements between the different health services involved in their care?

Methods

Study site and context

This study focusses on the use case of perinatal care and the sharing of data between an Aboriginal and Torres Strait Islander community-controlled birthing and perinatal service, Birthing in Our Community (BiOC) at the Institute for Urban Indigenous Health in SouthEast Queensland, Australia and a publicly funded hospital's maternity service.

Developed and implemented under Aboriginal and Torres Strait Islander leadership, and controlled by the local community, BiOC provides comprehensive, culturally informed birthing, perinatal and infant health services for Aboriginal and Torres Strait Islander families during pregnancy and birthing and for up to three years post-birth. During the immediate perinatal period BiOC partners with a publicly funded hospital's maternity service. Through BiOC, families have access to community-based hubs which are located close to where Aboriginal and Torres Strait Islander Peoples live and staffed by Aboriginal and/or Torres Strait Islander Family Support Practitioners (FSPs) and other workers who reflect the local community and provide wrap-around support grounded in Aboriginal and Torres Strait Islander ways of knowing, being and doing (see Kildea, Gao,[30] p.3 for BiOC's model of care). The success of these community-led services is evidenced in improved health (e.g., reduced rates of preterm birth–Kildea, Gao[30]) and social (e.g., reduced rates of child removals from families–O'Dea, Roe[31]) outcomes which counter enduring effects of colonisation.[31–33]

Methodology

This study was initiated by BiOC and cultural oversight for the study was provided by IUIH/BiOC. Indigenous and decolonising methodologies were employed, reflecting local Aboriginal terms of reference in SouthEast Queensland. Core elements of Indigenous methodologies, as outlined by Wilson,[34] include relationality, respect, responsibility, reciprocity, holism, and cultural integrity. These qualities align with national guidelines for Aboriginal and Torres Strait Islander research[35,36] and research quality.[37] We used an Aboriginal and Torres Strait Islander data collection method (yarning–Bessarab and Ng'andu[38]) and analysis approach (Thought Ritual—Yunkaporta and Moodie[39]).

Ethics approval was granted on the 15/06/2023, by The University of Queensland's Human Ethics Review Board (2023/HE000196). Informed consent was provided by all participants. Cultural and Intellectual Property (existing and that created through the research) were negotiated through a formal agreement.

Cultural protocol, and research reflexivity, involves locating ourselves in this research, considering “Who's your mob? Where are you from?” The authorship team comprises five Aboriginal and/or Torres Strait Islander people (including from Bundjalung, Wiradjuri and Gomeroi/Kamilaroi nations) and six non-Aboriginal and/or Torres Strait Islander people (born in Australia and Zimbabwe). The team has a diverse range of disciplinary backgrounds including Family Support Practice, Digital Science, Midwifery, Public Health, Sociology, Physiotherapy, Dentistry and Psychology. We see our diversity as a strength and are united in supporting the thriving of Indigenous Peoples. Our diverse experiences also provided ample opportunities for reciprocal learning.

Participants and recruitment

Two groups were invited to participate in this study:

1) FSPs aged 18 years or older and currently employed at the BiOC service. FSPs provide wrap-around cultural and psychosocial support to BiOC service users throughout their birthing and perinatal journey. All were Aboriginal and/or Torres Strait Islander people (a role requirement). Potential FSP participants were contacted through the service where service staff provided them with the study information and interested FSPs then provided contact details to the research team.
2) Pregnant people and those who had recently given birth who were accessing BiOC's services. As the service is specific to Aboriginal and Torres Strait Islander families, all identified as Aboriginal and/or Torres Strait Islander or had birthed/were birthing an Aboriginal and/or Torres Strait Islander baby. FSPs discussed the study with families who accessed the service and shared contact details for families interested in participating with the research team.

An Aboriginal woman from the IUIH research team (MBH) contacted all interested participants (FSPs and BiOC clients) and gained informed consent, offering individual and group yarning options depending on preferences and circumstances. M.B.H. conducted yarns in a private room at BiOC or via conferencing software. All were audio recorded and professionally transcribed. Data were securely stored at IUIH to ensure community control and ownership.

Data collection

We used yarning as a method of data collection which is derived from communicating, connecting and learning practices used by Aboriginal Peoples for millennia. Yarning involves informal, conversational discussions that allow participants to share their stories and knowledge in a relaxed and open manner, reflecting traditional ways of communication.[38] This method aligns with Aboriginal and Torres Strait Islander ways of knowing, being, and doing by prioritising relationships, community engagement, and non-linear knowledge sharing.[40]

We developed yarn guides in collaborative working groups including BiOC staff, IUIH researchers and UQ researchers. Open ended prompts were based on IUIH/BiOC's Social Health Yarn Tool (Fig. 1) to support participants to discuss their perspectives on sharing data between BiOC and the government-funded hospital service. Example questions for families were “Tell me a bit about yourself (prompt—mob, country and culture, client journey/story etc)” and “What information do you think should be shared between your midwife (hospital staff) and FSP (BiOC staff)”. Example questions for FSPs were: “What information about our mums would you like to see being shared between FSP (BiOC staff) and midwives (hospital staff)?”.

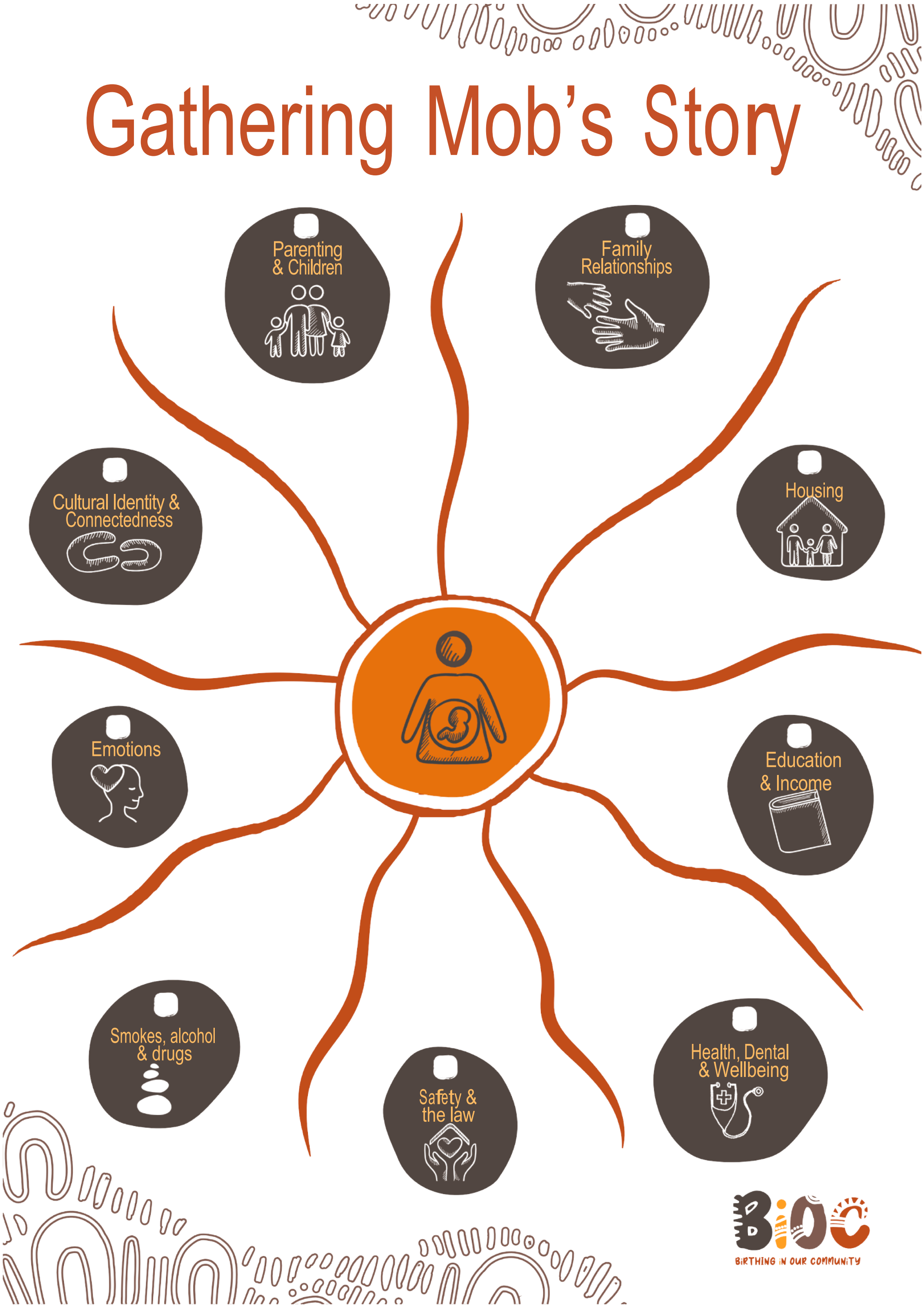

Fig. 1: **Birthing in Our Community's Social Wellbeing Yarning Tool - this tool was adapted to guide the research yarns in this project.**

Data analysis

Data analysis was informed by 'Thought Ritual,' an Indigenous approach to data analysis.[39] Thought Ritual is a reflexive process involving deep, critical thinking through the lens of Indigenous knowledge systems. It encourages participants to engage in interconnected, relational and holistic thinking. These processes foster a cyclical and reciprocal approach to knowledge, where learning is continuously shaped by the context and relationships involved. Analysis was therefore iterative—first, a subset of the data was shared with members of the research team (i.e., BiOC services, UQ and IUIH research) in two team analysis sessions where emergent concepts we discussed related to the research question. Summaries of these discussions were then shared with the broader research team for their input. Following this, M.B.H. returned to the dataset and selected key excerpts from the data that related to the emergent concepts. In collaboration with other team members this was refined into four key domains with exemplar quotes. These were then 'yarned back' to FSPs and then families accessing the services to include their insights into the analysis and to ensure relevance of results. Finally, all these relational elements were brought together in this manuscript with drafts reviewed and the analysis further refined as this report was produced. These inclusive approaches allowed multiple researchers and key stakeholders to be involved in the data analysis process, and for Aboriginal and Torres Strait Islander terms of reference and voices to be embedded in project outputs. For additional quality and rigour, we used The Aboriginal and Torres Strait Islander Quality Appraisal Tool.[37] All criteria were met.

Role of the funding source

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

Results

Participant characteristics

M.B.H. conducted eight yarns with 13 service users (two group, six individual yarns). Their ages ranged from 16 to 32 years, with most identifying as Aboriginal or Torres Strait Islander or both (the others were birthing, or had birthed, an Aboriginal and/or Torres Strait Islander baby). All identifying as women/mums, and for most this was their first experience at BiOC (n = 10) and first pregnancy (n = 7). M.B.H. also conducted two group yarns with six FSPs: all identified as women, and either Aboriginal, Torres Strait Islander or both. See Table 1 for more participant details.

Qualitative anlysis

The results discuss the importance of community control of what data are shared, how data are shared and with whom—and provides examples of the implications of data sharing. This is summarised under four interlinked and overlapping domains 1) *Power and Control in Data Sharing,* 2) *Safety Concerns,* 3) *Ability to Do My Job,* and 4) *Not Everything Should be Shared.* See Table 2 for an overview. Below, we use 'mums' for the service users as the commonly used term at BiOC and amongst Aboriginal and Torres Strait Islander communities, but we acknowledge that not all people who give birth identify as mums, and that BiOC also supports other family and community members. For confidentiality, mums are given pseudonyms and FSPs numbers.

Domain 1) Power and control in data sharing

Our analysis highlighted that data sharing arrangements can increase, reinforce or reduce power differences between services and can help or hinder Aboriginal and/or Torres Strait Islander communities being in control of their data. Who has access to data and how it is received is relevant to this issue.

Access to data. In our study site, the current circumstances were that the hospital staff (mainly midwives), had full access to client data created by BiOC staff (including FSPs) but not the reverse—very limited data were shared from the hospital to BiOC. This arrangement meant that the community-controlled organisation had less power, access and control over data than the non-Indigenous government hospital. FSPs minimal access to hospital records meant they had less visibility and control over how clients were supported. One FSP said *"a huge thing is we don't actually see any of their clinic notes or progress notes and things like that"* (003FSP), and another *"We'll just go off what the midwife has told us."* (001FSP). An example given was in relation to client intake. Access to the program, and triaging, is completed at the hospital so the FSPs cannot provide input into who enters the program or who is deemed 'high risk'. Mums deemed 'high risk' could mean they

Participant group (n)	Age range: years (n)	Gender (n)	Aboriginal &/or Torres Strait Islander Identification (n)	Pregnancies (n)	BiOC births (n)
Mums (12)	16–19 (2) 20–24 (2) 25–28 (1) 29–32 (3) Not provided (5)	Woman (12)	Aboriginal (7) Torres Strait Islander (1) Aboriginal & Torres Strait Islander (1) Aboriginal &/or Torres Strait Islander (1: unknown but identifies) Non-Indigenous with Indigenous baby (2)	1st (7) 2nd & 3rd (2) 3rd & 4th (2) 6th (1)	1st (10) 2nd (1) Unknown (1)
Family support practitioners (6)	N/A	Woman (6)	Aboriginal &/or Torres Strait Islander (6)	N/A	N/A

Table 1: **Participant demographics.**

Domains	Sub-domains
1) Power and control in data sharing Data sharing arrangements and circumstances can increase, reinforce or reduce power differences between services and, if established equitably, can help put community in control.	***Uneven access to data*** The implications of access to data for community control. The current state of the hospital being able to access community data but not the reverse meant unequal power and control over client care. Mums and Family Support Practitioners (FSPs) both wanted control over community data. ***How data is valued when shared*** At times, FSPs felt disempowered when their notes were accessed by midwives at the hospital due to their notes being considered less important or relevant because of their use of community terminology and phrasing. In contrast, our analysis suggests language based in community terms of reference is of high value.
2) Safety concerns Data sharing for service delivery purposes can enhance or reduce Aboriginal and Torres Strait Islander client and staff safety. Safety concerns discussed involved psychosocial and legal elements.	***Legal and child safety*** The main concern shared by both FSPs and mums was the risk of sharing information with the hospital service that could result in mums or families being criminalised and/or lead to child custody reporting. ***Psychosocial safety for mums*** Data sharing arrangements could affect mums' sense of psychosocial and cultural safety in other ways due to having to retell stories or FSPs not being adequately prepared to support mums and families. ***Workplace psychosocial safety for FSPs*** Judgement and stigma around approaches to note writing can affect psychosocial and cultural safety of the workplace.
3) Ability to do my job Effect of clinical data sharing arrangements on ability of Aboriginal and/or Torres Strait Islander staff to do their work. FSPs at times did not get the information they needed from hospital staff to do their work.	***Poorer care*** Without access to data from the hospital, it was more challenging for FSPs to understand the psychological, social and cultural context for them to provide the comprehensive care their service is designed to provide. ***Time wasted*** A lack of data sharing created extra work for FSP chasing up mums' contact information, appointment referrals and observation notes. ***Relationships affected*** Having that ability to access data can help to create strong relationships between the families and the services by providing context and helping staff be prepared for contact with service users. This could be disrupted if a significant incident had occurred at the hospital (for example, a traumatic birth) and the FSPs were not aware of this due to lack of access to data.
4) Not everything should be shared Most mums and FSPs do not want all information shared between the different services. Some mums discussed intentionally sharing different information with hospital staff and FSPs and like some aspects to be kept separate, while FSP's feel important for them to access all information.	***Perception of role and scope*** Some mums wanted the information they share with FSPs, and their hospital staff kept separate. ***Client and community agency*** Both mums and FSPs expressed the need for mums to have agency and individually consent to how their information is shared, having control over what is shared between services.

Table 2: **Overview of domains and sub-domains.**

are managed solely by the hospital and prevented from accessing community-led services. Another potential consequence is that they may not be appropriately prioritised–someone may be low risk clinically but should be more highly prioritised due to their social context. One FSP expressed understandable frustration at this lack of control and the resultant difficulty in providing culturally safe, trauma informed care: *"we look dumb… we're like the third hand man, so when the mums ring us asking us … we have to ring midwives or ring follow up, try and find out what the hell's going on"* (004FSP). This impacts continuity of care.

Throughout the shared care journey between the services, a lack of reciprocal data sharing sometimes meant that the community-controlled service had insufficient involvement in key client care decisions. FSPs highlighted how important their involvement was, with one of their key roles to provide culturally appropriate care for mums and families: *[hospital midwives] think in [their own] social emotional world … the midwives think mum is high risk, to which we would say: 'No, this mum's going to be okay'. (004FSP)* The FSPs and mums both highlighted how important the role of the community-controlled organisation was in circumstances like this—rating mum's as 'high risk' often resulted in (often inappropriate, stigmatising or unnecessary) higher surveillance, legal involvement and the potential loss of child custody. These implications are discussed further in Domain 2 below.

How data is valued when shared. A different, and perhaps more subtle, element of power and control related to data access was about the value that data is given when it is shared across services. Our analysis suggested there were instances were FSPs felt disempowered when their notes were accessed by midwives at the hospital due to their notes being considered less important or relevant (judged negatively) because of their use of community terminology and phrasing:

> *… because we haven't been to university and done the clinical and legal things of what to write and what not to write … So they laugh at ours because we are walking with these mums. We're not above them or better than them. We're writing our notes from our perspective … not the current midwife now, but there is one midwife here that laughs at our notes.*
>
> (004FSP)

Other participants agreed that it was important for staff, if they are working with Aboriginal and/or Torres Strait Islander communities, to value community's ways of doing things, communicating and living. These conversations highlighted the importance of community knowledges being embedded in service delivery, including through equitable data sharing arrangements: "*We live in community [...] Some things we class as normal, midwives think is outrageous or like crazy". (004FSP)*. Without proper context, community knowledges, stories and Aboriginal and Torres Strait Islander terms of reference, incorrect decisions and judgements might be made.

Although this devaluing of data shared by FSPs was notable in the yarns, this was not always the case, some FSPs expressed positive working relationships with midwives. For example, 002FSP said: "*They're ingrained here with BIOC and have learnt how it works and how to connect with the families and stuff."*. These positive experiences suggest more equitable power sharing relationships and control for Aboriginal and Torres Strait Islander people over their data are possible. However, given the varied experiences of community, this theme suggests that community control is better embedded when digital data sharing arrangements offer options for nuanced consent processes and what information is shared.

Domain 2) Safety concerns

This domain is about how data sharing for service delivery purposes can enhance or reduce Aboriginal and/or Torres Strait Islander client and staff safety. Safety concerns discussed involved legal and psychosocial elements.

Legal and child safety implications. The most dominant concern shared by both FSPs and mums was the risk of sharing information gathered at BiOC related to legal and/or child custody implications with the government-run hospital service. This included, for example, information shared by mums/family about substance use, current and previous family violence, or living environments (e.g., 'overcrowding'). Recording details about these aspects of mum's lives could result in hospital staff reporting families to Child Safety (i.e., government child protective services) with implications for criminalisation of mums and families, and child custody arrangements. FSPs discussed multiple examples of the mainly non-Indigenous staff at the hospital inappropriately evaluating which families are at risk, and a tendency towards over-reporting (e.g., even when events were in the past, or well managed).

> *It's a stigma ... unfortunately then these women are flagged by that hospital, and they're watched like hawks and they don't even get the information behind it. It's just the direct: 'They've had Child Safety okay yep we'll flag [them]'. Unfortunately, a straight jump to: 'You are now an issue.'*
>
> (002FSP)

As this quote alludes to, the over-reporting of child and family "safety issues" is often underpinned by racist assumptions and stigma that are enduring impacts of colonisation and assimilation policies resulting in criminalisation and disrupted cultural connections: *"[This] was actually the hospital to take their babies away when they were unwed [...] you have a lot of mothers who knew the history of [this hospital]" (001FSP)*. The FSPs discussed how these types of historical and ongoing embedded systemic racism are reasons why services such as BiOC have been created by local communities—BiOC's focus is on supporting women at risk of having Child Safety involvement and avoiding over-reporting:

> *[Hospital] and midwives, they're mandatory reporters. Where we advocate for our women with Child Safety. So, I've had times in the past where I've been hesitant to share information, just because it's like well if we share this information are they then going to be reported to Child Safety. When sometimes it's not necessary because we're working with the families like to avoid Child Safety involvement. Yeah, so I think not all information should be shared.*
>
> (001FSP)

Mums also expressed feeling safer sharing these aspects of their lives with FSPs than midwives, feeling less judgement and more understanding.

> *I'd feel more comfortable with my FSP... though that's because it's cultural then... where a lot of midwives, they don't have that experience so .... they wouldn't know the struggles... like without having to feel like you're being judged... when I was sharing with [FSP], she's like, "Yeah, sis, I went through this, too."*
>
> (Daisy)

Some FSPs and Mums reported that there were some staff at the hospital who understand and try to address the limitations and racism within their institution by make appropriate decisions—particularly staff directly connected to BiOC. Yet due to their location in a government-run hospital, with the context of historical and ongoing discrimination and racism within mainstream health services, it is understandable that their yarns often alluded to a general sense of lack of trust with sharing information that could have legal implications.

Psychosocial safety for mums. Data sharing arrangements could affect mums' sense of psychosocial and cultural safety in other ways. For example, when mums and families had to retell their stories due to the FSPs not having access data from the hospital service. This could have important psychosocial consequences for mums, adversely affect relationships with service providers, and be a barrier to accessing services:

> *Like it's traumatising to have to keep retelling their stories and that's basically that barrier blockage that's happening. It's a blockage for them even if it's just mental health it's still retraumatising [...] if I was referred here, I don't want to keep retelling my story.*
> (001FSP)

Further, FSP's may not have all the information to provide the appropriate support or connect mums with additional services (see Domain 3 below). Thus, there were secondary concerns with the lack of data sharing discussed in Domain 1 in terms of affecting mums' psychosocial and cultural wellbeing.

Workplace psychosocial safety for FSPs. Feeling a sense of loss of control and power resulting from data sharing arrangements has workplace safety implications for FSPs. As mentioned in Domain 1, many shared a sense of inequity because of the data sharing arrangements and feeling judged for the way they recorded information about clients. Aboriginal and/or Torres Strait Islander mums and FSPs want control of their own and their communities' stories and draw cultural strength through weaving stories, yarning and have oral histories that accurately document histories spanning millennia. Yet people working outside of Aboriginal and Torres Strait Islander terms of reference, due to Western and/or racist cultural norms and assumptions may negatively judge this way of communicating. This judgement is something the FSPs actively resisted internalising—an additional colonial and psychosocial load. Thus, data sharing arrangements have the potential to impact the psychosocial and cultural safety of the workplace for the Aboriginal and/or Torres Strait Islander staff.

Domain 3) Ability to do my job

This domain focusses on the effect of clinical data sharing arrangements on the ability of FSPs to do their work. FSPs at times did not get the level of information they needed from midwives at the hospital to be able to provide quality support for mums and families.

Poorer care. Without access to data from the hospital, it was more challenging for FSPs to understand the psychological, social and cultural context and for them to provide the comprehensive care their service is designed to provide. Highlighted by the FSPs, if they could have access to hospital data in real time, they could then consider factors that may have occurred during families visits to the hospital:

> *I can go to [a mum] and go, "Look, I've already read it and I can see what happened, can you elaborate a bit more." And she'd be more inclined actually to be open and go, "Yeah someone finally cared enough to actually read my story. Someone actually cared enough to listen."*
> (001FSP)

FSPs particularly highlighted the importance and benefits of having access to information related to mums' mental health, trauma, psychosocial needs, cultural Aboriginal and Torres Strait Islander context, legal, and child safety issues, so they could provide support and understanding to families.

Time wasted. A lack of data sharing created extra work for FSPs in following up mums' contact information, appointment referrals and clinical notes. As mentioned in Domain 1, this was, understandably, frustrating for FSPs as highlighted by this conversation in one of the group yarns:

> *006FSP: It'd just be nice if we can just log in [to the hospital system] and see it and go, "Yeah, this is what's happening." It makes sense, if we don't have to ask around.*
> *004FSP: And even to book transport for some mums because they don't have, they don't know, or they lose their paper or appointment or...*
> *005FSP: Change their phone number.*

The FSPs also discussed how time was often wasted through factors such as double ups or delayed referrals (e.g., to physiotherapy, smoking cessation, antenatal programs).

Affected relationships with mums. In providing culturally safe wrap around care, having the ability to access data can create strong relationships between the families and the services. Relationships can be disrupted if a significant incident had occurred at the hospital (for example a traumatic birth) and the FSPs were not aware of this due to lack of access to data. As one FSP mentioned when discussing incidents where this had occurred, they said that: *"Clinical issues can lead to mental health issues" (001FSP).* If the FSPs can know ahead of time through data sharing with the hospital then they can provide appropriate and meaningful responses, care and appropriate services to better support families.

Domain 4) not everything should be shared

Our analysis suggests that most mums and FSPs do not want all information shared between the different service providers. They emphasised the importance of mothers having the authority to decide how their information is shared, ensuring they have control over what details are communicated among health workers. Some mums discussed intentionally sharing different information with midwives and FSPs and prefer that some aspects are kept separate, while FSP's feel it is important for them to have access to all information from the other service due to its potential to impact the support they provide to families.

Perception of role and scope. Some mums wanted the information they share with FSPs at BiOC, and what they share with midwives at the hospital kept separate. FSPs were seen as "community for community" and being more connected to the social and cultural aspects of their care. Whereas the hospital midwives were considered to have roles relating mainly to medical issues (predominantly the physical aspects) of their birthing journey.

> *Yeah, if it's about my body or my health or anything, I would keep that to the midwife, but if it's about my personal, and then like what I need help with, or what I want, if I want to talk to someone, then keep that between the family support worker.*
>
> (Camila)

A few mums said they preferred to share fewer personal details with FSPs, as their close ties to the community posed a risk of information being shared with friends and family. Instead, they felt more comfortable confiding in midwives at the hospital. This variability further highlighted the importance of client agency in sharing of health information.

Client and community agency. Both mums and FSPs expressed the need for mums to have agency and ability to consent to their information between workers/services. FSPs expressed that not everything should be shared with midwives as oversharing with staff who are external to community can conflict with community responsibilities. They described a greater accountability for Aboriginal and/or Torres Strait Islander workers—it is within the workplace, but also amongst family and friendship networks: *"We have to answer to the community."* (004FSP)

Community agency also was affected by BiOC staff knowing (or not knowing) about the referrals and other details that affect the families' health and wellbeing journey. The FSPs argued that appropriate data sharing systems could support culturally appropriate service access:

> *… if the midwives were to send a referral, we would then automatically be told about what they have done … [then] if we have people who are available here in a culturally appropriate space, then shouldn't they be [offered as an option]?*
>
> (002FSP)

When FSPs are not aware of what is happening with their clients, they cannot ensure that families have choices about their care.

The above suggests that most mums and FSPs prefer data sharing mechanisms that enhance community access to and control of data, including mums' control over their information and selective sharing of information between service providers.

Discussion

This study explores the concept of custodial stewardship for the ethical sharing of Indigenous Peoples' data across digital health platforms to ensure that data sovereignty is upheld. It builds on Indigenous scholarship arguing that digital health and IDSov can have competing interests,[4,5] and explores this issue empirically using a case example of sharing Aboriginal and Torres Strait Islander people's health data in a perinatal care setting. In our case example, government-run hospitals have considerable control over Indigenous data even when partnering with community-controlled organisations. Critical new findings in this paper highlight several ways in which IDGov practices such as custodial stewardship could be enhanced that should be considered by those working with Indigenous health data.

Our analysis points to how essential it is that Indigenous organisations and communities lead the establishment and maintenance of reciprocal data sharing agreements and infrastructure to ensure their benefit to community. Our findings suggest that data sharing practices without sufficient custodial stewardship can reinforce existing power imbalances, have safety implications and affect service delivery. Other Indigenous scholars similarly emphasise that IDGov must be grounded in relational accountability, ensuring that data governance aligns with community values and priorities.[4,24,41] Carroll, Garba[42] underscore that strengthening these frameworks requires continued advocacy to dismantle entrenched systems of control over Indigenous data. Our analysis also suggests that while data sharing can help empower a community's control over their healthcare, not everything should be shared. Systems that enable individual consent where possible, and flexible processes for what is shared and with whom, would support culturally appropriate and effective care.

Recommendations

To address these findings, several recommendations can be made. First, shifting towards a more balanced risk management approach that considers the benefits of data sharing for community empowerment and healing could mitigate privacy violations and exploitation. While some information must remain confidential to protect client privacy, overly restrictive data sharing can hinder effective service delivery.[43] In developing a more balanced risk management approach, it is crucial to acknowledge the pressures faced by hospital employees regarding mandatory reporting requirements. The prevailing mindset—'if in doubt, report, or risk losing my license'—can lead to withholding of information and sharing it with hospital generalists not connected to community. This systemic pressure has led to over-reporting, and serious and often avoidable consequences for community—such as the over-representation of Indigenous newborns in out of home care.[31] Aligning with principles of Indigenous authority and control over Indigenous data, enhancing data access for community-controlled organisations would improve the capacity to deliver culturally safe, trauma-informed care. However, this needs to be balanced with the values and preferences of clients in terms of types of level of information they want shared between services. Addressing this dynamic through education and policy adjustments would support more nuanced and ethical data-sharing practices.

Second, it is necessary to resource the development of data and digital infrastructure that will support reciprocal and nuanced data sharing and realise IDGov and IDSov. Without such critical systemic and structural changes, data-sharing transformation will be limited, and the risks of data sharing heightened.[4] Third, developing tailored leadership strategies that prioritise community voices and leadership, and reflect the unique cultural dynamics of each Indigenous community, is crucial. Indigenous communities have the right to exercise ownership over Indigenous health data, with mechanisms in place to ensure that data sharing aligns with local Indigenous cultural values and community priorities.[44] When developed in alignment with local Indigenous governance structures, data sharing can help address power imbalances by embedding Indigenous authority, values, and protocols into data use.

A fourth priority involves providing education and training for healthcare providers from non-Indigenous-led organisations on the significance of IDSov, IDGov and local approaches such as custodial stewardship. This is likely to enhance understandings of the historical contexts and ethical considerations involved and improve relational accountability.[41] Fifth, establishing collaborative leadership frameworks that centre Indigenous Peoples in the governance of data-sharing initiatives is important to ensure community interests are prioritised. Finally, implementing mechanisms for ongoing evaluation of data-sharing practices allows for adaptability and responsiveness to community feedback and changing circumstances.

These steps collectively support the creation of a data-sharing environment of ethical obligation to uphold Indigenous sovereignty via localised methods of IDGov and relational accountability. As the research reported in this publication forms part of a larger digital infrastructure project, the next steps are to create the platforms, policies and procedures to support the implementation of these principles.

Methodological considerations

Although the principles and concepts produced through our analysis are likely to be broadly applicable in similar contexts (for example, across Australia and in other colonised countries in the global north), local differences should be considered. For example, local Indigenous ways of knowing, being and doing as well as local hospital and health service systemic and social norms. This paper also intentionally focuses on the perspectives of Aboriginal and Torres Strait Islander staff and clients in the community-controlled sector, however there would be additional insights from hospital staff when understanding data sharing arrangements.

Conclusions

This paper examines the complex interplay between the risks and benefits associated with sharing healthcare data for Indigenous communities. The increasing digitisation of health records presents both opportunities for improved healthcare delivery and significant challenges regarding privacy, autonomy, and cultural sensitivity. Through a consideration of relevant literature and examining a case study, this paper aimed to provide a nuanced understanding of how data sharing can be both beneficial and detrimental for Indigenous Peoples.

This article explores local knowledges and experiences relating to sharing healthcare data within and beyond Indigenous communities. It emphasises the need for considerations of agency, transparency, and ethical obligations when integrating data-sharing practices in health systems serving these populations. By examining the socio-cultural dynamics and historical context of Indigenous Peoples, the article argues that establishing and maintaining IDGov mechanisms such as custodial stewardship is an ethical obligation for all involved to ensure effective data sharing upholds data sovereignty, and community control.

By prioritising community leadership, transparency, and cultural values, healthcare systems can create a supportive environment that enhances health outcomes while respecting the rights of Indigenous communities when sharing data. Future efforts to build data sharing infrastructure should focus on integrating the recommendations we have shared above into data-sharing designs, frameworks, government policies and service level practices and procedures, ensuring that Indigenous Peoples lead decisions affecting their health data. While data sharing is generally encouraged, it must be designed and implemented in ways that uphold, rather than compromise, Indigenous self-determination and governance.

Contributors

Cultural governance was provided by KWa, MBH, DM, CMu, AE and JW. Conceptualisation involved all authors but particularly KWa, CN, CMa, JS, MBH, KWi and NR. JS, CMa, MBH and CS wrote the first draft of the manuscript and all authors contributed to successive iterations. JS, CMa and MBH have directly accessed and verified the underlying data. The literature search was conducted by JS, CS and NR. Data production and curation was undertaken by MBH, CM and JS. Formal analysis was undertaken by all authors but particularly KWa, MBH, JS, JW, CN, KWi and CM. Funding acquisition involved CN, CS, KWa, KWi and NR. The methodology was based on cultural knowledges and conceptualised by the whole team–particularly KWa, JS, CMa, MBH, KWi and CN. Project administration was provided by MBH, KWi and CMa. All authors were responsible for the decision to submit the manuscript.

Data sharing statement

Due to Indigenous Data Sovereignty principles, individual participant data will not be available.

Declaration of interests

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