Empowering communities through data literacy: a qualitative study exploring Indigenous Australian perceptions, engagement and understanding of data.

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Abstract

Data literacy is an essential competency needed to use data to inform decisions and participate in contemporary society. Importantly, in the context of Indigenous health it enables engagement with health services and facilitates health management, Indigenous data sovereignty and Indigenous data governance. However, while Indigenous data sovereignty and Indigenous data governance are gaining momentum globally, there are no mechanisms for understanding or enhancing data literacy within Indigenous communities. To explore this, a research project was co-designed between the QUT Centre for Data Science and the Aboriginal and Torres Strait Islander Community Health Service Brisbane (ATSICHS), a community-controlled health service in Queensland Australia, to provide insights into the current state of data literacy, community perceptions of data, and identify community suggestions for enhancing data literacy. Furthermore, by utilizing an Indigenist research design, the project ensured Aboriginal and Torres Strait Islander Peoples' ways of knowing, being, and doing were privileged and prominent throughout research design, data collection and analysis. The qualitative study included 20 semi-structured interviews with Brisbane Aboriginal and/or Torres Strait Islander Peoples who had accessed or engaged with ATSICHS. This paper presents insights into Aboriginal and Torres Strait Islander Peoples' perspectives on data and data literacy, which may benefit community-controlled organizations and other Indigenous communities within Australia and around the world.

Keywords: Data Literacy; Indigenous Health; Indigenous Research; Data Sovereignty; Data

Governance

Introduction

Data is not a new phenomenon. However, as it becomes more accessible through digital formats, people are required to critically assess data in its various forms, at increasing rates and, in all aspects of their lives (Metzger & Flanagin, 2013). The ability to critically assess, analyse and argue with data requires a degree of literacy. There is not one single definition of literacy and it can also be described in the context of specific communities or groups. UNESCO (2008, p. 18) defined functional literacy as being able to "*engage in all those activities in which*

literacy is required for effective functioning of his (her) group and community and also for enabling him (her) to continue to use reading, writing and calculation for his (her) own and the community's development". The term has also evolved to describe competency in specific areas such as information literacy, digital literacy and financial literacy (Bonikowska et al., 2019). Various definitions of data literacy are proposed and it is often described in conjunction with statistical literacy and digital literacy (Bonikowska et al., 2019; Mund & Bergner, 2023). Data literacy can also be described as "*the ability to understand and use data effectively to inform decisions*" (Mandinach & Gummer, 2013, p. 30) and that it "*enables individuals to access, interpret, critically assess, manage, handle and ethically use data*" (Koltay, 2015, p. 9). Gebre's (2018) literature review identified two main perspectives of data literacy oriented around (i) competency and (ii) empowerment. The competency-oriented perspective focuses on technical skills required for using, analysing and interpreting quantitative data. The empowerment-oriented view goes beyond technical skills and describes data literacy as "*a means to foster civic engagement*" (p. 333). This perspective also considers data privacy, data ownership, community engagement and social justice, and suggests that data is important in everyday decision-making (Atenas et al., 2023; Gebre, 2018; Mund & Bergner, 2023). People are often required to make judgements from data and to decide how their personal data is collected, used, stored and shared (Wolff et al., 2016) and in Australia enhancing data literacy among Aboriginal and Torres Strait Islander Peoples (hereafter 'Indigenous Australians'[1]) is a national priority (Department of the Prime Minister and Cabinet, 2020).

Although Indigenous[2] knowledge systems have developed over millennia and are complex, data about Indigenous peoples contributes to the 'deficit discourse' which permeates commentary on Indigenous policy (Chatterjee, 2017; Perry & Holt, 2018; NCAI Policy Research Center, 2017). This is seen in many colonised countries. Government policies in the United States, Aotearoa (New Zealand), Canada and Australia are informed by data portraying Indigenous disparity and disadvantage (Fogarty et al., 2018; Meyer, 2012). There is now a call for strengths-based approaches to counter the dominant deficit discourse surrounding Indigenous data (Thurber et al., 2020). The exclusion of Indigenous peoples in the production of Indigenous data has resulted in this deficit narrative (Walter & Suina, 2019).

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[1] We respectfully use the term "Indigenous Australians" to refer to Aboriginal and Torres Strait Islander Peoples who are the First Nations Peoples of Australia.

[2] We respectfully use the term "Indigenous" when referring to First Nations peoples globally, collectively and/or internationally.

To redress this deficit data approach (from mostly non-Indigenous researchers) that torments Indigenous populations, it has been suggested Indigenous peoples should "*gather their own data for data sovereignty*" (Lopez, 2020, p.148) and that data should be collected by the Indigenous communities it is about (Kelaher et al.,2018).

Indigenous data sovereignty (IDS) is described as the right of Indigenous peoples to govern the collection, ownership and application of data about Indigenous communities, peoples, lands, and resources (Kukutai & Taylor, 2016), and it is critical to the self-determination of Indigenous Australians (Pholi, 2009; Walter & Andersen, 2013). The inclusion of Indigenous peoples in the collection of data allows for proper community protocols and practices to be followed and ensures the data is collected and used in a way that represents the community (Lopez, 2020). Indigenous data governance (IDG) is the enactment of IDS and includes the practices and processes in which data is managed (Griffiths et al., 2021; Lovett et al., 2019).

The Aboriginal and Torres Strait Islander Community Health Service Brisbane (ATSICHS) is a community-controlled organisation that has offered services to the Brisbane and Logan Indigenous Australian communities since 1973. With 12,000+ clients and engagement with 40% of the Brisbane Indigenous Australian community, ATSICHS is one of the largest community-controlled health services in Australia. ATSICHS offers services for all aspects of life including medical and dental clinics, child and family health services, youth services, social and emotional wellbeing programs and services, a midwifery hub, an aged care facility, and a variety of family and child support services including child protection, family wellbeing services, kindergarten programs and a child and family centre (ATSICHS, 2020).

This study was co-designed between the QUT Centre for Data Science and ATSICHS to better understand the engagement of community[3] with respect to data, and for service improvement. Furthermore, to ensure proper process and to meet the needs of the community, more understanding of the current state of data literacy and perceptions of data within the community was needed.

Enhancing data literacy is important for Indigenous Australians because it essential for effective engagement and communication with health services, personal health management and data sovereignty. However, while there has been a movement toward ensuring good IDG

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[3] The term "community" is used when referring to members of the Indigenous Australian community.

processes, for example the CARE Principles developed by the Global Indigenous Data Alliance (2018), and the National Indigenous Australians Agency's Framework for Governance of Indigenous Data (2024), and improvements around data infrastructure and research capability within Australia, as led by the Australian Research Data Commons (2021), there has not been any specific focus on improving data literacy within Indigenous Australian communities. The National Agreement on Closing the Gap (Department of Prime Minister and Cabinet, 2020) Priority Reform Four states that there should be "Shared access to data and information at a regional level"(p.13) and there is a commitment to "build the capacity of Aboriginal and Torres Strait Islander organisations and communities to collect, and use data" (p.14) however prior to this study there was very little understanding of data literacy in the context of Indigenous Australians.

The research questions addressed in this study are:

1. What is the baseline level of data literacy in the community?
2. How do Indigenous Australian communities engage with and use data?
3. Do Indigenous Australians want to enhance data literacy? If so how could ATSICHS assist?

This paper addresses this gap within the literature and presents a novel case study which highlights community perspectives on data literacy, and considers data sovereignty and data governance.

Methodology and theoretical framework

It was important to frame this study in a way which honours Indigenous perspectives and experiences, even if they are not obvious to non-Indigenous peoples or understood within the Western context. Nakata's Cultural Interface, which has been extensively used in education research, was applied as it provides exploration of the contested space between Indigenous knowledge systems and Western knowledges (Nakata, 2002, 2007a, 2007b). Experiences of Indigenous Australians are influenced by the tensions existing between these two knowledge systems. The application of Indigenous Standpoint Theory allows for the interpretation of these experiences within the Cultural Interface by providing a lens to understand how Indigenous Australians view the world and theorise these experiences from an Indigenous perspective (Moreton-Robinson, 2013). Indigenous Standpoint Theory highlights Indigenous perspectives, knowledge systems and experiences while challenging dominant Western paradigms (Moreton-Robinson, 2013; Nakata, 2007a). This approach is significant as Indigenous peoples have unique ways of knowing, being and doing (Martin & Mirraboopa, 2003). It is how Indigenous peoples view the world and in this context it may influence the way Indigenous Australians speak about data and data literacy.

The application of the Cultural Interface, together with Indigenous Standpoint Theory have been utilised extensively in research pertaining to Indigenous Australians (see for example Cook et al., 2023; Krakouer, 2023; Martin et al., 2017; McLaughlin et al., 2014). These theories were a good fit for this study as they also align with the Indigenous Research Methodology and the qualitative approach to the research.

Methodology

The research employed an Indigenous Research Methodology (Martin & Mirraboopa, 2003; Rigney, 2001; Smith, 2013). This approach was selected to privilege Aboriginal and Torres Strait Islander Peoples' ways of knowing, being, and doing in research design, data collection, and analysis. Utilising qualitative research methods in Indigenous methodology is well documented and considered (see for example Botha, 2011; Cook et al., 2023; Corporal et al., 2020; Carlson & Kennedy, 2021; Lowe et al.,2019). The first and second authors are Aboriginal Australians and the participant recruitment activities and interviews were undertaken by these members of the research team.

We had Indigenous researchers leading the data collection in accordance with the AIATSIS code of ethics and best practice. When conducting research with Indigenous communities it is important to acknowledge the potential biases that may arise from a researcher's relationships with community members. To mitigate these biases, participants were fully informed on the aims of the research project and our role as Indigenous researchers, and by discussing research findings with other non-indigenous research members of the team.

Participants and data collection

As a large part of the community engages with ATSICHS, it was determined participants would be Aboriginal and/or Torres Strait Islander adults who have connected with ATSICHS in any capacity and were not limited to current clients of the heath service. Indigenous Australian protocols such as exhibiting respect, yarning, and identifying yourself culturally and geographically, were followed when engaging with all participants. Ascertaining community perspectives was crucial to ensure an Indigenous Research Methodology was followed and principles in relation to Indigenous Data, IDS and IDG were incorporated into the findings (Maiam nayri Wingara Indigenous Data Sovereignty Collective, 2022).

Participants shared information through semi-structured interviews using an interview guide (Appendix A). A benefit of this approach was the flexibility to tailor questioning to the individual and insight open responses (Cohen et al., 2018) in relation to

how community perceive and use data. Example questions included, "What do you consider to be Indigenous data?", "How confident are you to use data", "Can you give me an example of how you use data?" and "Do you want to improve your understanding of data?". Interviews occurred at locations around Brisbane between September and December 2022. Recruitment of participants occurred until a point of data saturation, where no new information or insights were offered, was reached (Guest et al., 2020). At this point, 20 participants were recruited. The demographic details of the participants of this study, are displayed in Figure 1.
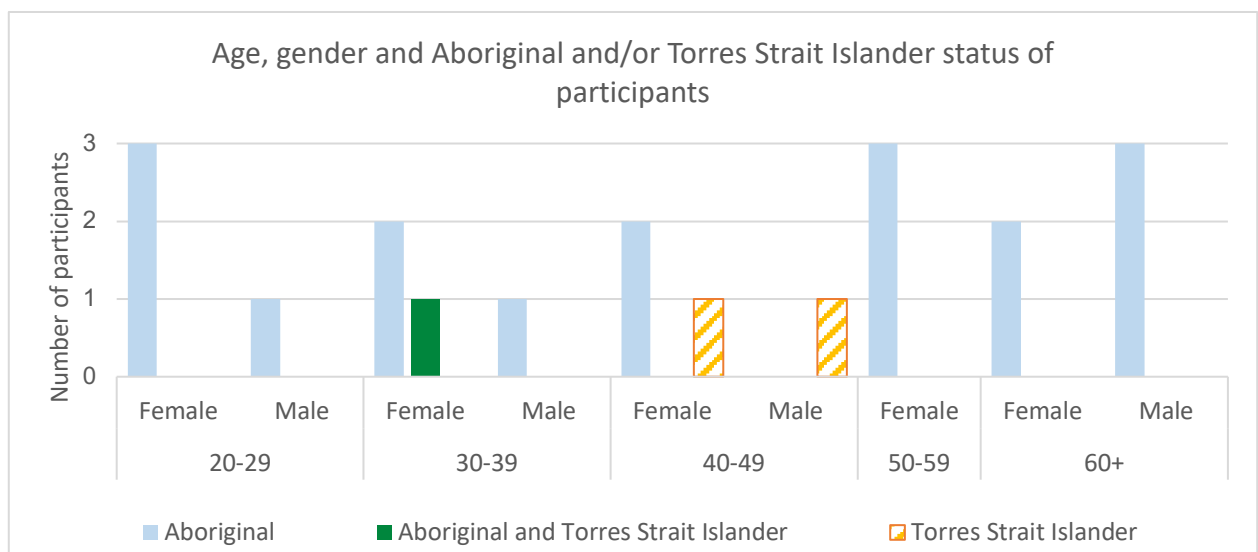

Figure 1. Demographic details including gender, age range and Aboriginal and/or Torres Strait Islander status of participants.

Ethical considerations

This project was approved by the QUT University Human Research Ethics Committee (5813-HE31). Ethical considerations for working with Indigenous Australians and Communities were adhered to within this study. The AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research (2020) principles of Indigenous self-determination, Indigenous leadership, impact and value, sustainability and accountability were followed.

Sampling

A combination of convenience and purposive sampling was used to recruit participants (Cohen et al., 2018). Convenience sampling occurred through recruitment activities at various community events including National Aboriginal and Islander Day Observance Committee

(NAIDOC) week. NAIDOC activities provided the opportunity to speak to many Aboriginal and Torres Strait Islander community members about the study. Purposive sampling ensured that the study included a diverse range of Aboriginal Peoples, Torres Strait Islander Peoples, ages, and genders.

Interviews and data analysis

Interview recordings were automatically transcribed. Transcripts were de-identified and underwent thematic analysis. The data analysis process follows an approach described by Braun & Clark (2012) and used for "identifying, analysing and reporting patterns (themes) within the data" (p. 79). This approach required six steps: (1) data familiarization; (2) initial coding; (3) compiling codes into themes; (4) review of themes; (5) definition of themes; and (6) reporting of findings (Braun & Clark, 2012) and is outlined below:

1. The first step of the thematic analysis involved data familiarization. Interviews were listened to in conjunction with reading the transcripts and at this stage any transcription errors were amended.
2. In step two, deductive themes were first created from the initial coding of responses relating to each of the three research questions as well as any final comments. These were saved into four files which were uploaded into NVivo.
3. Next inductive themes were identified through using the NVivo word frequency query.
4. Each transcript file was then examined for the repeated or common themes across each participant and coded into sub themes in a codebook.
5. The codebook was used to cross check connections across the interviews and define themes.
6. The themes are described further in the next section.

Results and discussion

Data collected provided insights into perceptions of data and the current state of data literacy, how data is being used and engaged with, and how data literacy could be enhanced within the Indigenous Australian community.

Perceptions and understanding of data

The first research question exploring the baseline level of data literacy in the community was explored through questions relating to the participant's understanding of data, such as what

it is, where it comes from, how confident they were to use data and what Indigenous data might be. Participants first thoughts on hearing the word 'data' included: information, statistics, words, interviews, qualitative, quantitative, collection, numbers, privacy and research. Data was also described as being personal and more than numbers,

> I've looked at data and considered it as members of family because data in a broader sense is considered. Materials collected through research and research can be conducted at community level and family level about family history, kinship about artifacts or objects, language (Participant 6).

Participants proposed that data comes from people, individuals and communities. Indigenous data was described as data collected from or about Aboriginal and/or Torres Strait Islander peoples, but also cultural knowledge such as *"any data about First Nations people or any data or information about First Nations cultural and intellectual property, including the environment, country and those sorts of natural resources"* (Participant 7). It was also suggested Indigenous data required consideration of data sovereignty,

> So, for me Indigenous data, I actually class it under data sovereignty because there is a thing called Indigenous data sovereignty. And that sovereignty is around about what we want to get data on. Basically, what happens right now is data is drawn from us, from criteria that we've had no say in, so I'm kind of tapping into data sovereignty content. But I think Indigenous data is around whether data is about what we want to get, not what we've been told we have to get. So Indigenous data to me is about that (Participant 10).

Participants were asked to self-indicate their confidence level of using data and their responses are indicated in Figure 2.
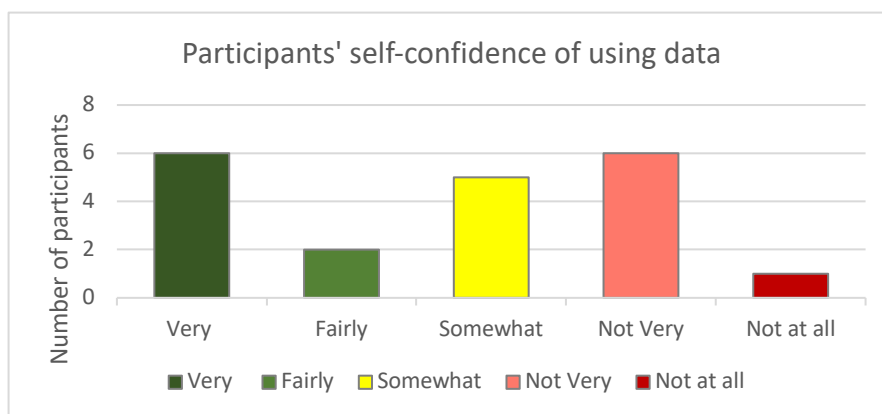

Figure 2. Participants self-confidence of using data

The term 'collecting data' evoked responses centering around the importance of following proper process when collecting data from Indigenous Australians for example, *"What comes to mind is what's the purpose of the data being collected and what would the data be used for is what automatically comes to my mind"* (Participant 17). Data use was identified to be important, and if used correctly can be beneficial to individuals and communities as explained,

> I think using data can be beneficial if it's used in an appropriate manner and there's no sort of foregone conclusion in where it's going to take you. But I think when you're looking for a specific answer, it can be easy to manipulate data to reflect that. So, I'm cautious of people using data to back up theories when, you know, if perhaps they're not using an appropriate process (Participant 19).

The final question in this section explored participants' perceptions of the term 'data literacy' and whether it was familiar. Most responses indicated the term was unfamiliar, however acknowledged it related to the understanding of data or using data. Participant 10 suggested,

> I think when I hear about data literacy, I think it's about empowering. Well, anything to do with the word literacy I think is about empowering our mob to understand data. That's what I'm hoping the data literacy about and that's what I think it could be.

Use of and engagement with data

Questions in this section sought to answer the second research question, exploring how do Indigenous Australian communities engage with and use data, and focused on how data was currently perceived, used, and consumed by participants and their communities. 18 participants advised they used data everyday such as at work, study, to assist in decision making or to monitor their health and activity.

> Well, data is a part of your everyday life, whether you realise it or not, I guess. I've got kids, sometimes it's weighing them, sometimes it's, I'm checking their height, I'm checking their weight, because, you know, sometimes I need it for health service (Participant 17).

The tools participants used to make sense of those data included computers, phone apps, internet, and human. This included their own interpretation, knowledge or research

skills as well as advice sought from family, community or healthcare professionals (if concerning healthcare).

Participants suggested that data was helpful in personal and work/education settings, *"It helps me plan. It helps me recognize when things aren't right. It helps me manage and manage my finances, manage my health, manage my work"* (Participant 7). Personally, data could help with budgeting, predicting the weather, or improving health outcomes. Professionally it was identified that data would help to track performance and identify areas to focus on and used to make change. Participant 9 explained that data impacts our everyday lives,

> Well for me with uni, it helps me make sense of what I'm writing about and makes sense of supporting my argument. But I think it's also helpful as it's pointed out, data impacts our daily life. So, from data there are improvements in I guess healthcare or anything.

Over 50% of participants expressed concerns around interpreting and understanding data. Additional challenges included access to data. *"I think the biggest challenge is data is very hard to access at times"* (Participant 17) and how data may not represent Indigenous Australians through a cultural lens such as *"I think for Aboriginal Torres Strait Islander people, sometimes data can contribute to further stereotypes instead of looking at room for help"* (Participant 9), or *"with Aboriginal Torres Strait Islander Peoples, if they're talking to people or, you know, referring to people from remote communities, I live in Brisbane City"* (Participant 19). Participant 10 also highlighted further how data collected through surveys can be challenging as she explained her interactions with community surrounding Australia's 2016 Census of Population and Housing (Census),

> I'll give you an example. In 2016, the census question right at the end asked everybody, "Do you have access to internet via multiple devices?" And everyone ticked yes, we're going to tick yes. But I would then say to them, "But that means you have availability, is internet available here all the time, can you access the internet all the time? Do you have coverage?" And they go, 'Oh no, I don't have coverage, but I can still access the internet.' And then the other question I said is, "can you afford to get coverage in this area?" 'No, I can't afford it, I don't need to get it now'.

From these participants, it was identified that data can be both positive and negative, depending on where it comes from and how it is used or interpreted.

> Sometimes it can be a good thing because we need this data, we need this information to be able to live. But then you do also have the bad side, which

the wrong people could get your data, can get your information and use it
the wrong way (Participant 3).

This feeling was also present when asked about websites collecting data.

Yeah, well there's been a few instances where they've been hacked a lot of services
and data on, big companies too, so that's a bit frightening. But people use data, I
think it's good and bad. But you do need data to clarify things, I think (Participant 3).

When asked about data in relation to ATSICHS, participants had knowledge around
the data that was collected for example around how it was used for reporting, funding
allocation and development of services to meet the community's needs. Furthermore, there
were suggestions on how data held at ATSICHS could be useful to the community and how it
could be shared with community to improve outcomes and engagement with the services, as
explained *"Hey look, based on the data got, we were able to access these additional services
because you provided us with the correct story"* (Participant 10).

The remaining questions in this section explored understanding and importance of IDS
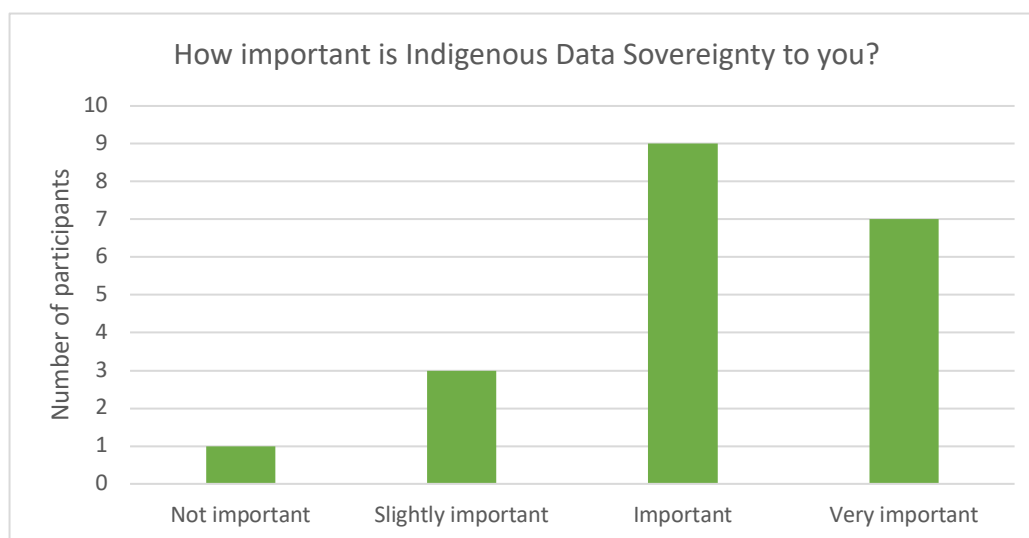and figure 3 displays participants' perceived importance.

Figure 3. Importance of Indigenous Data Sovereignty

IDS was described, *"Well, data sovereignty is about our ownership of your own data
and having control of who has access to the data"* (Participant 17) and identified as important,

So, it's again, saying that we need to be in control of that, you know? Yes.
And that doesn't mean that we can't share it. That means we need to be in
agreeance with who owns the data (Participant 18).

The remaining two participants stated they did not use data in their everyday lives and did not suggest how data could be helpful or challenging. One participant did not know how websites may use their data, or how data might be used or shared at the health service. They also did not want to know about how their data was used at the health service. The other was concerned about websites collecting and selling their data, so they did not put data into websites. They did, however, suggest that data could be used to help the community and they would like to know more about it.

Improving Data Literacy

The final question section explored research question three; whether Indigenous Australians wanted to improve their data literacy and if so, how ATSICHS could assist with this. It was first asked whether based on their knowledge, data literacy was important, and 19 participants agreed that it was. Participant 20 explains,

> I think so because in the complex world that we live in today with news headlines about a report on this or statistics on that, you know, all these, this data that informs our decisions, it's important to have a good understanding of, if not where this data has come from, but to be able to understand in general how it's gotten there and to know the language of data.

Additionally, the same 19 participants also suggested they would like to enhance their data literacy. Participants suggested limitations to enhancing data literacy could be an individual's location and resources as well as the constant negative data that is presented to communities. The assumption data it is overly technical could also be a barrier as Participant 15 explains,

> The language to explain it, often is kind of, not very accessible. I think a lot of the time you have to be very educated to be able to understand it in the way that it's explained. Even just how to, like knowing how to access it.

Suggestions for how ATSICHS could improve data literacy in the community varied between participants,

> I think the best way to do it is through a conversation. When, you know, community is presenting themselves at an appointment. Have, a simple yarn about what data literacy is and how, you know, you're collecting the information, what's happening with it (Participant 17).

Suggestions for ways ATSICHS could better share the data it collects with community included, text messages, newsletters, social media, emails and notices within the clinics. It was also suggested there could be an individualized health portal. Participants also wanted to see how their health was tracking in the data,

> So whatever information they have captured, being able to see the key points and see that journey. If I come in every week or every month for a period of time and they're always take my blood pressure, I want to know, I want to see that, is my blood pressure improving (Participant 8).

They also wanted to be able to access this information regularly, "*Not make it just a yearly discussion where they bring it up months later, try and talk about how it impacts me right now. And I guess just being transparent*" (Participant 9). It was also noted it was important to consider privacy and permission from the person the data was gathered.

Final comments

Lastly participants were given an opportunity to add any additional comments or thoughts. Most reiterated their previous responses around the importance of data literacy. Participant 15 mentioned the interview had been thought provoking,

> I guess this has just, the interview has brought to my attention how, I didn't realise that this was an area of interest. I do want to know how my data is used, how much data's being taken, who's looking at the data, and if it is just actually about funding to help people or if it can be, if there can be sort of negative consequences of certain data being out there.

Discussion

Results exploring each of the research questions underwent thematic analytic as previously described. Six themes were identified. These were (1) data literacy views and (2) determining data literacy; importance and perceptions of (3) IDS and (4) IDG and community suggestions how the health service could empower the community to (5) enhance data literacy and (6) effectively engage with data. Through the lenses of Indigenous Standpoint Theory and Cultural Interface Theory, these finding are discussed in the three following sections: Describing and determining data literacy, Community views of IDS and IDG, and Enhancing and empowering data access and engagement.

Describing and determining data literacy

The current level and nature of data literacy in the community was influenced by individual perceptions, understanding and use of data in their everyday lives. Frank et al. (2016) argues a degree of literacy is required for people to make use of data and there are numerous approaches when considering what the term 'data literacy' encapsulates. Before considering data literacy, it is important to understand the word 'data' has many different meanings, particularly so when considering what might be 'Indigenous data' and what Indigenous Australians may consider to be data. The Maiam nayri Wingara Indigenous Data Sovereignty Collective (2018) explains "*in Australia, Indigenous Data refers to information or knowledge in any format or medium which is about and may affect Indigenous peoples both collectively and individually*" (p.1). Participants explained that data could be anything from the weather report, statistics and spreadsheets to Indigenous Australian knowledges, practices and artifacts,

> I think it's the way that we live and be and operate within this world, Indigenous data is distinct. We all take it in different ways, but that's guided the way that we view what we're looking at and that kind of thing is viewed by our own positionality. And so, me as an Aboriginal woman, the way that I perceive things or data is different or because I think there's a set of assumptions and values which is placed on how we produce and what we choose to look for while we think that's valuable (Participant 2).

Participant 2 has also identified they live within two worlds and they themselves are sovereign. Therefore, data relating to them is sovereign data. Indigenous peoples engage with both Indigenous knowledge systems and Western knowledge systems. Nakata (2007) described the Cultural Interface as our 'lifeworld' where Indigenous knowledges and Western knowledges meet, impacting our decisions, experiences and understanding in everyday life. Data literacy can be considered in this context, as Indigenous Australians engage with both what could be considered Indigenous data and non-Indigenous/Western data, and their understanding of and engagement with data is influenced by both cultural and western

discourses. This positionality is relevant when Indigenous Australians make decisions surrounding their own lives particularly in relation to healthcare as depicted in Figure 4.
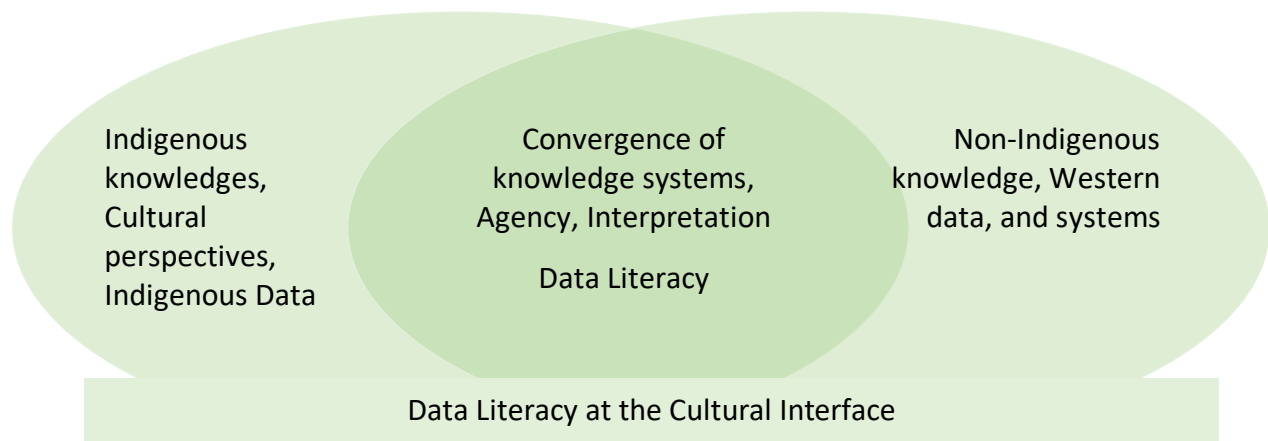

Figure 4. Data Literacy at the Cultural Interface

Data literacy is essential for making data informed decisions. As participants identified diverse use of data, there was no single determinant of when an individual may be considered 'data literate' or how participants compared to each other. Participants' confidence levels of using data depended on what type of data was in question, such as for work, or information that was available on the internet. The more familiar the data was, the higher level of confidence in using it was described. If a participant was frequently required to engage with data, there was a higher degree of data literacy and understanding of how data was collected, used and shared. Lastly, results also indicate there was a strong desire for participants to have a say in and know how their data was being used and interpreted in relation to their health and provision of ATSICHS services.

Community views of IDS and IDG

IDS is the right of Indigenous peoples to have a say in how data about them is collected, used and shared. Kelaher et al. (2018) argue evaluation of data collected should be led and owned by the Indigenous Australian peoples and communities it is about. Walter and Suina (p. 237, 2019) further propose,

> Data sovereignty is practiced through Indigenous data governance, which assert Indigenous interests in relation to data. The primary vehicle is Indigenous decision-making across the data ecosystem; from data conception to control of access to and usage of data. Indigenous decision-

> making is a prerequisite for ensuring Indigenous data reflects Indigenous priorities, values, culture, life-worlds and diversity.

The concept of sovereignty has been enacted by Indigenous Australians for millennia (Bishop, 2021). Moreton-Robinson (2007) provided further insight into what sovereignty means for Aboriginal and Torres Strait Islander Peoples from an Indigenous Australian perspective and it has been described as part of our ontology and epistemology and also as the right of Indigenous Australians to control their lands including who and what is on it (Bishop, 2021). It was clear from the results of this study that data sovereignty is important to Indigenous Australians and critical to keep culture strong. Participant 20 explains, *"based off the name data sovereignty sounds like protection of data and only people who have a good reason to access it, accessing it. And so given that data sovereignty, is important to me."* Indigenous Australians want a say when their data was concerned as Participant 6 stated *"Data sovereignty? Nothing about us without us."*; and Participant 19 expanded,

> In the sense that there should be someone that's clearly an owner of this data and is responsible for it, but also at the same time owning and being responsible for it means that they also have obligations to the people that they've collected it from and for the purpose that they were going to use it for.

How data is collected and used by ATSICHS is important to community members, and generally the community trust ATSICHS are going to maintain good Indigenous data governance practices. This was supported by the results, in particular by one participant who did not think IDS was important and advised it was not something he knew about or wanted to know about when considering the 'private' data that was held at ATSICHS.

Enhancing and empowering data access and engagement

For data to be useful, people must be able to take information from it and this requires a degree of literacy (Frank et al., 2016; Metzger & Flanagin, 2013). The importance of being able to use data in everyday life was also recognized by the participants in this study. There was a desire to improve their data literacy and knowledge of how data collected by ATSICHS is used.

Enhancing data literacy amongst members of the Indigenous Australian community was identified by the participants as a key factor in community empowerment and self-determination and the importance of data sovereignty in self-determination is also argued by Walter and Anderson (2013). Atenas et al. (2023) argue marginalized groups are at greater risk of succumbing to a data literacy divide and *"social realities may aggravate data injustices"* (p.5), so enhancing data literacy is important also for social justice, from grassroots level

through to policy levels. Increasing data literacy could provide Indigenous communities with the skills to access, interpret and utilize data for their benefit. This capability can lead to more informed decision-making, improved resource allocation, and greater participation in societal processes. Data literacy fosters community empowerment by enabling individuals to tell their own stories through data. It provides a platform for Indigenous voices to be heard in arenas where data-driven decisions are made, further promoting self-determination and agency.

Additionally, by having a greater understanding of (a) what data is held by ATSICHS, (b) how data is used by ATSICHS community members could make decisions about their health and see how their sovereign data is used to improve community wellbeing. Participant 2 suggested there could be meetings or awareness-raising campaigns to ensure the community knows what is collected. This sentiment was echoed by Participant 5 who suggested information could be shared through *"pamphlets, text messages and community engagement"*.

When exploring how to enhance data literacy in the community, participants identified there were barriers to data literacy, and addressing these could enhance data literacy. Access to data is increasingly through digital platforms and this can be a barrier to Indigenous Australians engaging with data. Barriers identified included,

> Power, internet, mobile, phone, even level of education, incarceration, transport if they need to get to somewhere, of course, having a computer or some formal medium to access data (Participant 7).

It is therefore important that these are considered in any data literacy initiative. Participants suggest data should be presented in ways that are accessible, *"the language to explain it, often is kind of, not very often, not very accessible. I think a lot of the time you have to be very educated to be able to understand it in the way that it's explained"* (Participant 15), and that can be easily understood.

It was also suggested that skills and understanding of data could be embedded into their regular interactions with the health service as explained by Participant 8,

> As part of an annual check-up, where time is allocated to looking at my health overall at a glance and actually seeing that change over time. So whatever information they have captured, being able to see the key points and see that journey. If I come in every week or every month for a period of time and they always take my blood pressure, I want to know, I want to see that, is my blood pressure improving?

It has been identified there are broad perspectives within the community when it comes to understanding and engaging with data in everyday life and with data collected by

ATSICHS. There are a range of data literacy competencies, and a powerful desire to enhance capability when it comes to data and community members suggested ways the service could assist to build this capability. By viewing these findings through an Indigenous Standpoint, recommendations can be suggested.

Recommendations

The following recommendations have been proposed following the thematic analysis and consider suggestions made by the participants.

1. Develop a data literacy awareness campaign.
2. Incorporate opportunities for data literacy capacity building in existing client touch points.
3. Continue to engage with community about their understanding of data and how it is collected, used, stored and shared by ATSICHS and provide opportunities for community to engage with their personal data.
4. Explore the possibility of a client portal to allow community members access and engagement with their health and wellbeing data.
5. Develop a culturally appropriate data literacy training program targeted at different audiences such as healthcare professionals and community members and evaluate its effectiveness.
6. Continually incorporate community feedback into service delivery and initiatives.
7. Continue a practice of strong Indigenous Data Governance mechanisms.
8. Explore possible technologies that could assist with enhancing data literacy in Indigenous Australian communities.

Based on feedback, recommendations for enhancing data literacy could be embedded into existing practices and touch points between ATSICHS and the community such as during regular health checks, feedback surveys, social media and hard copy media such as signage or pamphlets. Further research could include, exploring the effectiveness of the recommendations and the development of a competency tool to track or measure data literacy levels.

Limitations

Limitations to this study include, time constraints, the sample size and variation of participants within the sample. This study was funded for 12 months by the QUT Ignite scheme, therefore there were time constraints surrounding the duration of this study. As this project sought responses from Indigenous Australians, a full human ethics application was

required. This process included appropriate community consultation which utilized a proportion of time.

Initially, participants were expected to primarily be recruited at NAIDOC events, however due to the delay in obtaining ethical clearance and the postponement of several community events due to extreme weather, recruitment of participants took longer than expected. While 20 participants from a variety of backgrounds, genders, ages and education levels were recruited, we acknowledge this may not accurately represent the 12,000+ clients of ATSICHS.

Conclusion

In consultation with ATSICHS, this study aimed to lay a foundation for developing a framework for understanding and improving data literacy in the Brisbane Indigenous Australian community. Through understanding the current state of data literacy; how data is perceived, used and consumed; and whether there is a desire to enhance data literacy, this research has provided explicit information and recommendations which could be used to enhance data literacy within the Indigenous Australian community.

By using an Indigenist research design, this study sought and enabled the interpretation of the experiences with, and perceptions of, data that Indigenous Australians have in order to answer the research questions. The findings of the 20 semi-structured interviews were discussed as: Describing data and determining data literacy; Community views of Indigenous Data Sovereignty and Indigenous Data Governance; and Enhancing and empowering data literacy, access and engagement.

This study identified that the Indigenous Australians who participated want to enhance their data literacy and also their understanding of how data is collected, used and shared by ATSICHS. It has also provided recommendations and strategies that could be used to further enhance data literacy within the community and inform the community around how data is collected, used and shared. Work is currently underway on recommendation 4, exploring the possibility of a client portal to allow community members access and engagement with their health and wellbeing data. Future work will be based around the other recommendations and will aim to develop a framework for enhancing data literacy within Indigenous Australian communities and organizations.

Acknowledgements

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Appendix A

INTERVIEW GUIDE

We will be interviewing using semi structured questioning in relation to these three questions.

The three research questions we will investigate are:
1. What is the baseline (i.e., current nature and level of) data literacy of the community that engages with ATSICHS?
2. How is data currently perceived, used and consumed by different members or groups within the community that engages with ATSICHS?
3. Do members of the community that engages with ATSICHS want to improve their data literacy, and if so how can ATSICHS help with this?

Protocol of Acknowledgement and Introduction
Interviewer to introduce themselves and where they are from, Acknowledgement of Country.

Introduction Questions for all participants
We will begin each interview with basic greetings such as asking how they are, did they get there okay, and would they like a glass of water and so on.

At this stage we will go through the ***Information Sheet*** with them. We will read out and ask them to sign the ***Consent Form*** and make sure we turn on the recorder.

Then we will start the interview process with these questions.

General questions
- Can you please tell me a little about yourself?
- What is your name please? How old are you? What is your gender? Who are your mob/ where are you from? What is your level of education? How long have you been a client?

We will explain to each of the participants that we are going to ask questions about data literacy at the ATSICHS Brisbane.

This is the order of the questions to guide the interviews for each of the individual participants. Each participant will be interviewed individually.

1. What is the baseline (i.e., current nature and level of) data literacy of the community that engages with ATSICHS?

- What do you think of when you hear the word data?
- What are some examples of that data?
- Are there other definitions of data you can think of?
- Where do data come from? What do you consider to be Indigenous Data?
- How confident are you to use data?
- What do you think of when you hear the term "collecting data"?
- What do you think of when you hear the term "using data"?
- What do you think of when you hear the term data literacy?
- One definition of data literacy is "the ability to understand and use data effectively to inform decisions"
- Can you tell me about what you know about data literacy?

2. How is data currently perceived, used and consumed by different members or groups within the community that engages with ATSICHS?

- Can you give me an example of how you use data in your everyday life?
- What tools do you use to make sense of that data?
- In what ways are data helpful to you?
- In what ways do data pose a challenge?
- Do you see data as a good thing or a bad thing or some combination of the two?
- How do you feel about websites collecting and/or using your data? How do your family, friends or community members feel?
- Do you know what data they collect?
- Do you know what they do with this data?
- Who should have access to that data?
- Do you know what sort of data is collected at the Aboriginal and Torres Strait Islander Community Health Service?
- How might data held at health services be useful to the community?
- Can you describe how data might be shared or used by ATSICHS?
- Would you want to know more about how your data are used?
- What do you know about data sovereignty?
- Is data sovereignty important to you?

3. Do members of the community that engages with ATSICHS want to improve their data literacy, and if so how can ATSICHS help with this?

- Based on your knowledge of data, do you think that data literacy is important (if yes can you explain why).
- Do you want to improve your understanding of data?
- (if yes) What would you like to understand more about data?
- Do you think community members would want to improve their data literacy?
- Would you want to increase your knowledge and understanding of data in the ATSICHS?
- What may limit the data literacy in the community?
- How would you like to see ATSICHS help with enhancing data literacy within the community?
- How would you like to see ATSICHS maintain data sovereignty?
- How do you think ATSICHS could improve how they use your data?
- How could ATSICHS better share the data it collects with you?

Final Questions for all participants
- Would you like us to contact you so you can provide further feedback on the findings from this study?
- Do you have any other thoughts or comments you would like to share?

End of Interview