



Yarning about Aboriginal Health Research Data in Boorloo (Perth)

Community Report

Supported by:





The translation of the Noongar greeting
on the cover and throughout the report is:

***“I acknowledge families here tonight
Standing on Noongar land
Healing our families
Healing our head
Healing our heart
Healing our hands”***

Artwork in the report has been adapted from
original work by Kristy Rodney.

This publication may contain names and faces
of Aboriginal people who have passed.

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Acknowledgement of Country, stories and knowledges

Ngaala kaaditj Whadjuk Noongar moort keyen kaadak nidja boodja

We acknowledge the Whadjuk Noongar people as the original custodians of the land this project was created on, and we pay respect to Elders past and present.

We also acknowledge that sovereignty was never ceded. Just as Aboriginal people have both a right and an enduring connection the land, water and sky, they also have a right to govern their stories, knowledges and culture.

In this project, we have sought to humbly engage in deep listening to understand the voices of Aboriginal participants. In other words, we have tried to engage with the koort (heart) as much as with the kaat (head).

We recognise that universities and research institutes are colonial institutions. For this reason, Wungening Aboriginal Corporation (Wungening) and Aboriginal colleagues from these institutions have worked together to uplift Aboriginal voices.

That's because there is wisdom in Aboriginal stories and knowledges from all walks of life. Participants have told us they want a report written in the voice of the local Aboriginal community, even if it's a report with a set of recommendations for researchers and health services. In fact, accessibility is one of the key principles of Aboriginal Data Sovereignty.

We therefore ask researchers and health services to listen with the koort and the kaat, to sit with and respect the participants' wishes and voices throughout this report and its interim recommendations.





Note on language

Participants and the Community Group called for us to use words that speak to and empower the Aboriginal community. We have therefore made this report as accessible as possible, with minimal use of jargon and acronyms. Where we unavoidably use unfamiliar terms, such as Aboriginal Data Sovereignty,¹ we explain what it means in clear language.

Throughout this report we respectfully use the term 'Aboriginal' to refer to Aboriginal and Torres Strait Islander peoples. We acknowledge the rich diversity of cultures, languages and experiences within these communities, and recognise that terminology preferences vary among individuals and communities. We use this term with the intent of inclusivity and respect. In some places where referencing another author who has used the term 'Indigenous' or 'Aboriginal and Torres Strait Islander', we have kept their terms.

When we mention 'stories', we aren't simply referring to yarns or 'data' in the way most researchers define it. We mean the story of the data's journey – every time we hand information over to researchers and services, as well as what happens to that information. There's a desire among participants that data represents the full story of their lives.

¹ Explained in detail on page 15

Funding

We gratefully acknowledge support for the project which came from a range of sources: The Kids Research Institute, Edith Cowan University (ECU), Murdoch University, a Murdoch University partnership with the WA Health Translation Network's Consumer and Community Involvement Program, and Lotterywest for Wungening's *Decolonising Data, Evaluation and Research* project which also contributed to this project.

Ethics approval

The project received ethics approval from the Western Australian Aboriginal Health Ethics Committee (WAAHEC HREC 1289) and reciprocal ethics approval from Murdoch University (2024/003).

Suggested citation

Uink, B., Liddelow-Hunt, S., Wear, K., Dau, D., Andrews, L. (2025). Yarning about Aboriginal Health Research Data in Boorloo (Perth): Community Report. Wungening Aboriginal Corporation.

Summary

Aboriginal people have a right to assert how the information – or data – about us is collected, stored, accessed, analysed, presented and distributed. This is particularly important when it comes to data about our health because it is information that helps us understand what keeps us well and what makes us unwell. And it includes our own ideas for staying healthy.

Health researchers have always collected, and will continue to collect, health information from us. Data and research can benefit us if it's done the Aboriginal way – by prioritising Aboriginal voices about health research and keeping this data safe and within community control. As a result, this project was led, designed, analysed and controlled by Aboriginal people for the Aboriginal community in Boorloo.

The project is the result of several years-long conversations between a group of Aboriginal researchers and Wungening about the need for local ways to talk about Aboriginal Data Sovereignty. What that means is that we as mob should have community ownership over the collection and use of our data. This data can be any information collected about Aboriginal people, including research data, service data, pictures and videos. As a study team, we were all equally committed to hearing from our wider community about how Aboriginal Data Sovereignty could practically be achieved in health research in Boorloo.

One of the barriers we face in achieving full data sovereignty is the institutionalisation of research. Many research projects are administered through universities who often hold and dictate how our data is stored, deleted or re-used. In contrast, this project has been led by an Aboriginal community-controlled organisation that has control of the data on behalf of the community.

Through yarning with Aboriginal people, this project aimed to understand community ideas on how to keep Aboriginal health research data safe and ensure the Aboriginal community controls it.

We wanted to have a yarn about

What community understand health research data is

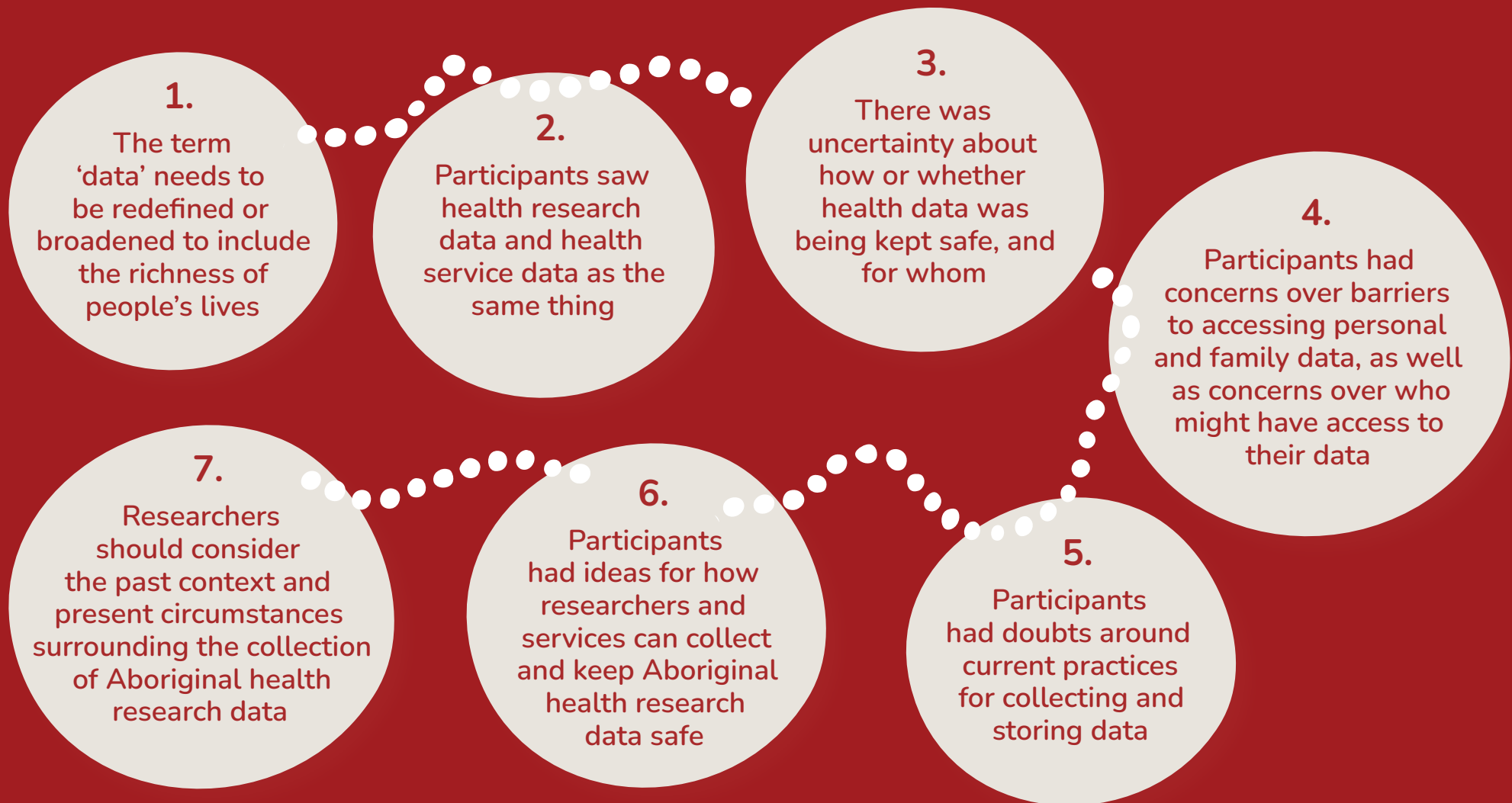
What community understand about Aboriginal Data Sovereignty

Ideas on how to manage health research data for Aboriginal peoples living in Boorloo

In this report, we outline key findings and recommendations based on the participants' views.

Findings: in brief

Participants often spoke about the importance of having their personal stories heard, respected, and honoured in the collection of health data. In brief, this is what we found:





*“It’s gotta be
truth-telling.”*

– PARTICIPANT AT THE YARNING EVENT

Boorloo Aboriginal peoples’ ideas for Aboriginal Data Sovereignty fit with national and international standards of Indigenous Data Sovereignty, like the Maiam nayri Wingara principles.

The interim **recommendations** concluding the report flow from the voices of the participants. The principles for Aboriginal Data Sovereignty in Boorloo have been based around the five Maiam Nayri Wingara principles of Indigenous Data Sovereignty and what these principles look like in Boorloo. They offer direction on practical action for researchers. Importantly, learning and practicing the principles of Aboriginal Data Sovereignty requires humility from researchers and institutions. The concept of humility can be challenging for researchers, yet it is necessary for research with Aboriginal people.

Who was involved?



32

Aboriginal participants
at the initial community
yarning event



9

People elected to the
ongoing Community Group



Majority Aboriginal study team
from Wungening, ECU,
The Kids Research Institute
and Murdoch University



Support from WA Health Translation
Network's Consumer and Community
Involvement Program team at the
initial community yarning event

The study team

The study team members were from Wungening Aboriginal Corporation, ECU, The Kids Research Institute and Murdoch University. The WA Health Translation Network's Consumer and Community Involvement Program provided support at the community yarning event:

Kiesha Wear (Chief Investigator)
Wungening Aboriginal Corporation

Christine Almond (previous Chief Investigator)
Wungening Aboriginal Corporation

Prof Bep Uink
ECU (formerly of Murdoch University)

Shakara Liddelouw-Hunt
The Kids Research Institute

A/Prof Chanelle van den Berg
Murdoch University

Cheryl Bridge
The Kids Research Institute

Mara West
The Kids Research Institute

Daniel Morrison-Bird
Wungening Aboriginal Corporation

Jackie Oakley
Wungening Aboriginal Corporation

Donna Pickett
Wungening Aboriginal Corporation

Colleen Wheelock
Wungening Aboriginal Corporation

Jessica Leslie
Wungening Aboriginal Corporation

Ashlee Anderson
Wungening Aboriginal Corporation

Kelli McIntosh
The Kids Research Institute

Lindey Andrews
Wungening Aboriginal Corporation

Dr Duc Dau
Wungening Aboriginal Corporation

Lucy Spanswick
Wungening Aboriginal Corporation

Louise Southalan
Wungening Aboriginal Corporation

Laura Dent
Wungening Aboriginal Corporation

Consumer and Community Involvement Program Team

Ingrid Laing
WA Health Translation Network

Kerry Mace
WA Health Translation Network

Kat Stewart
WA Health Translation Network

Jillian Northwood
WA Health Translation Network

Deb Langridge
WA Health Translation Network

The Community Group

The Community Group is made up of community Elders and young people who self-nominated after the initial yarning event.

Hosted by Wungening, the group brought a cultural and community lens to all aspects of the research. Members contributed to understanding the findings and provided feedback on the analysis and recommendations. They also guided the writing of the report by providing advice on style and language.

Working with them involved a two-way learning process. While they imparted their lived experience and cultural expertise on the project, the study team supported this to happen by providing the group with data sovereignty workshops and visual resources. These workshops and resources helped enhance the group's meaningful engagement with the research findings, recommendations and report writing.

Key relational and respect elements the study team cultivated included:

- Having Aboriginal facilitators
- Engaging in deep listening and acting on what we heard by meaningfully incorporating feedback, perspectives and advice into the report
- Creating the space and taking the time needed to have genuine involvement from the Community Group.

The Community Group worked on this project over a period of 18 months, meeting every two months. Membership has evolved over time, with some individuals attending consistently and forming a stable core, while others participated on a more ad hoc basis depending on their availability or interest in specific topics.

Members have included:

- Aunty Barbara McGillivray
- Aunty Shirley Thorne
- Jenny Bonney
- Aunty Beryl Weston
- Marie Taylor
- Carol Palmer
- Justine Farrell
- Lionel Quartermaine
- Lorraine Pryor
- Marissa Mippy
- Paige Smith
- Darren Thorne
- Cheryl Taylor





Why this study?

Doing data and research the Aboriginal way

Aboriginal people are increasingly making it clear to researchers that we have a right to have a say over the information – or data – they collect about us. This is particularly important when it comes to data about our health. We are talking about information that will help us understand what keeps us well and makes us unwell, along with our own ideas for staying healthy in the future. Our rights also include knowing what this data is and having a say about how it is used and who should access and store it.

Unfortunately, as Palawa scholar Professor Maggie Walter points out, there's a lot of data *about* Aboriginal people, but it's usually not for or by us. That kind of data often fails to tell our story. It's what Professor Walter calls *BADDR* data (Walter 2018). If the words 'research' and 'data' are either negative or confusing for some of us, it's partly because it's *BADDR*.

What *BADDR* means is that many researchers and governments have collected and told the stories of our data in a way that **blames** us if our health is bad. These researchers and governments can often mix information about the health experiences of all mobs into one group of 'Aboriginal people' (**aggregates**). The stories they tell about our health might not explore the full context of our lives (**decontextualised**). Instead, these stories might focus on what is going wrong for us instead of what is working well (**deficit**). Finally, mob only have limited ways to access our own health research data (**restricted**).

Aboriginal Data Sovereignty pushes back against *BADDR* data, by showing us that data and research can benefit us if it's done the Aboriginal way.



What is Aboriginal Data Sovereignty, and why does it matter?

Aboriginal Data Sovereignty is a new word for an old concept. As mob, we've been researchers, storytellers and custodians of knowledge since time immemorial. But the concept of Aboriginal Data Sovereignty exists because keeping our knowledge and stories safe is different to how it was done in the past.

While Australia wide it is referred to as Indigenous Data Sovereignty, at a local level we use Aboriginal Data Sovereignty. However, we use the term Indigenous Data Sovereignty when talking about national and international contexts.

So, let's see what others have said about it before we come back to Boorloo.

In 2018, Aboriginal researchers Ray Lovett, Maggie Walter, Gawaian Bodkin-Andrews and Vanessa Lee founded the Maiam nayri Wingara Indigenous Data Sovereignty Collective. It has become the leading Indigenous Data Sovereignty group in the country working to uphold the rights of Aboriginal people to own and control data that is about them, consistent with the United Nations Declaration on the Rights of Indigenous Peoples (Maiam nayri Wingara & Australian Indigenous Governance Institute, 2018).

The group's name comes from different language groups. **Maiam** means 'Welcome', and is from an Eastern Island language, Meriam Mer, of the Torres Strait. **nayri** (which is uncapitalised) is the palawa kani word for 'good', as in a good and important thing. **Wingara** is from the D'harawal Traditional Descendants and Knowledge Holders Circle, and it refers to thinking and understanding (Maiam nayri Wingara, n.d.).²

Networks like Maiam nayri Wingara exist across the world, and they include:

- The [US Indigenous Data Sovereignty Network](#) (USIDSN) in the USA
- The [Te Mana Raraunga - Māori Data Sovereignty Network](#) in Aotearoa (New Zealand)
- The [First Nations Information Governance Centre](#) in Canada.

All of these networks met in 2019 to form the Global Indigenous Data Alliance (GIDA).

Maiam nayri Wingara defines Indigenous Data Sovereignty the following way:

Indigenous Data Sovereignty refers to the right of Indigenous peoples to exercise ownership over their data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, distribution, and reuse of Indigenous data.

(MAIAM NAYRI WINGARA & AUSTRALIAN INDIGENOUS GOVERNANCE INSTITUTE, 2018)

² The Eastern Island groups include Mer (Murray Island), Erub (Darnley Island) and Ugar (Stephen Island). palawa kani is the Aboriginal language in Tasmania today. Dharwal Country is along the NSW coast.

What this means is that we as mob should have community ownership over the collection and use of our data. Data is any information collected about Aboriginal people including research data, community services data, pictures and videos.

The Maiam nayri Wingara Indigenous Data Sovereignty principles build on international Indigenous Data Sovereignty movements and assert the rights of Indigenous peoples to govern their data in accordance with self-determination.

Principle 1

Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.

Principle 2

Data that are contextual and disaggregated (available and accessible at individual, community and First Nations levels).

Principle 3

Data that are relevant and empowers sustainable self-determination and effective self-governance.

Principle 4

Data structures that are accountable to Indigenous peoples and First Nations.

Principle 5

Data that are protective and respects our individual and collective interests.

How the five principles of Maiam nayri Wingara Indigenous Data Sovereignty look and sound for mob in Boorloo, with help from the Community Group

Principle 1:

This means Aboriginal people have the power to decide what happens to our knowledge, information and stories. We determine how they are created or developed, where and how they're kept, why they're being used, and who gets permission to use them.

Principle 2:

This means that our knowledge, information and stories are told to show the full picture, and that this picture is available and accessible in a way that helps us understand what affects us directly, what works for us, why things might be the way they are.

We can see the picture for each person, each community, and the whole country. The stories told reflect our diversity as Aboriginal people. Our stories make sense of the present by understanding the past.

Principle 3:

This means that we collect the knowledge, information and stories that our communities need to make informed decisions in a lasting way. Stories are collected to empower Aboriginal people, not so that others can make decisions for us.

Principle 4:

This means that the people who collect our knowledge, information and stories follow policies and processes that are led by Aboriginal people.

Principle 5:

This means that our knowledge, information and stories are collected, stored and used in a way that uplifts, respects and protects the needs of individuals and the community.

Aboriginal Data Sovereignty in Boorloo

Over the last couple of years, researchers and organisations have been getting better at applying Aboriginal Data Sovereignty principles, but there's still a long way to go. There are national and international guidelines for Aboriginal Data Sovereignty, but no guidelines specific to Boorloo.

To make sure local mob's data is being protected *our way*, we need to apply the principles to meet the needs and wishes of Aboriginal people in Boorloo. Many researchers are becoming more aware of the need for Aboriginal Data Sovereignty. Yet there hasn't been much instruction or community consultation on *how* they could ensure mob in Boorloo can keep ownership of the data they provide to researchers.

Overall, we began this project with the question "What does Aboriginal data sovereignty for health research data look like in Boorloo?" Because of our dedication to health, healing and wellbeing, we chose to focus on Aboriginal health research data.

We defined Aboriginal health research data as information that mob here provide about their health and health practices as part of a research study. To answer the question, we asked community members how they would like to control their health research data. From their answers, our goal was to develop a set of local recommendations that researchers could use to ensure Aboriginal ownership and cultural safety in Aboriginal health research.

Wungening's Decolonising Data, Evaluation and Research project

Wungening is heavily involved in collecting data for its programs and research and evaluation projects. The organisation also helps researchers by recruiting participants for advisory committees, interviews, surveys and focus groups.

These activities are historically driven by funders and partners whose priorities do not always reflect Aboriginal ways of knowing, being and doing. Mob's relationships with each other, the land, our knowledges and storylines are what shape our ways of knowing, being and doing (Kennedy, 2022). Wungening has witnessed firsthand how research and evaluation that's not done our way disempowers Aboriginal organisations and communities. A culturally unsafe way of doing things doesn't fulfil the potential of data to improve the wellbeing of Aboriginal people.

Wungening has made inroads in recent years but also hopes to improve the situation for clients and the community with Lotterywest funding awarded at the end of 2023 for the Decolonising Data, Evaluation and Research project. Over the two years of the project, Wungening has been working to help undo the negative impact of colonial thinking on data and research.

The organisation's goal has always been to shift the power back to the community, making sure Aboriginal people are involved in deciding how data is collected, used and shared. The project isn't just about numbers – it's about us taking back control over our information. The goal is for information to tell Aboriginal stories the right way, and for it to be useful to the community.

What does 'decolonising data, evaluation, and research' look like in practice? This project is one example. It's the second time that Wungening has led a project with external research partners and, on behalf of the Aboriginal community, has had full control of the data and how it's used. The first project was the Birdiya Maya Homelessness Research Project (Birdiya Maya Project Research Team, 2023). For that project, Wungening received the Lowitja Institute's Tarrn doon nonin Aboriginal and Torres Strait Islander Health Research Ethics Award, which rewards deadly research that's in line with Aboriginal ways of knowing, being and doing.

Ultimately, Wungening hopes to create an environment that honours not just the power of personal experience but also the wisdom of community. The organisation continues its commitment to lobbying government, researchers and services about why Aboriginal Data Sovereignty is important. And we want to put it into practice through agreements.



Community ownership in practice

Birdiya Maya Homelessness Research Project

Wungening and National Drug Research Institute, Curtin University

The Birdiya Maya (Elders Voice) project is a research project led and owned by the Aboriginal community. It focused on hearing directly from Aboriginal people about their experiences of homelessness in Perth – how it feels and what needs to change. The idea for the project came from local Noongar people who have been affected by their own or others' homelessness. The project was supported by Lotterywest and led by Wungening, in partnership with Curtin University. This partnership showed a real shift in power, giving control to the community. The project created a space for Aboriginal people to tell their stories and share their ideas in their own words and images, with the goal of helping governments and services take action to reduce homelessness for Aboriginal people in Perth.

The project was guided by a Community Ownership Group, made up of 15 Aboriginal Elders chosen by Elders Groups from across Perth. Wungening made sure that all research information belonged to the community and took steps to protect people's stories and data. For example, Wungening's agreement with Curtin University had to align with the Maiam nayri Wingara Data Sovereignty principles, which support Aboriginal control over their own data. All the data is stored by Wungening and managed by Aboriginal people through the Community Ownership Group or the Wungening Board.

This means Aboriginal people decide who can access the data, how it's used and how it's shared. This is very different from most university research, where the data is usually owned and controlled by the university, not the community.

The research team included Aboriginal researchers, including a Noongar Chief Investigator, which helped make sure the work was culturally safe and led by the community. Wungening also employed two respected Elders to lead community engagement, working with Wungening's Noongar Community Engagement Lead. Their involvement made sure that everyday decisions were guided by cultural knowledge. Instead of focusing on "building capacity," the project recognised and centred the skills and strengths Aboriginal people already have.

Strict protocols require that all data use be approved by Wungening and the Community Ownership Group. This includes all access to and use of the data, and expectations for Aboriginal people to be involved in any analysis of the data and in the review and endorsement of any reports or publications. These safeguards ensure Aboriginal people retain authority over their data, demonstrating Wungening's strong commitment to Aboriginal Data Sovereignty.





Walkern Katatdjín (Rainbow Knowledge)

*The Kids Research Institute, ECU, Kulbardi
Aboriginal Centre at Murdoch University,
the University of Western Australia*

Funded by the National Health and Medical Research Council, the study aims to understand the social and emotional wellbeing, mental health and service needs of Aboriginal and Torres Strait Islander LGBTQA+ young people. The project is led by Aboriginal investigators, including Aboriginal LGBTQA+ investigators and staff (Principle 1). The idea for the research came from Aboriginal and Torres Strait Islander LGBTQA+ community advocacy (Principle 3). Looking at the wellbeing of LGBTQA+ youth within Aboriginal and Torres Strait Islander communities is an example of breaking down the collected information into smaller units to provide a more complete story of vulnerable groups within larger groups (Principle 2).

The project is owned by Aboriginal and Torres Strait Islander LGBTQA+ community members in two ways: 1) a Governance Committee made up of Aboriginal and Torres Strait Islander LGBTQA+ community members from across Australia and 2) an Aboriginal LGBTQA+ Youth Advisory Group.

Both groups provide input and final say on the design of studies undertaken through the project as well as final say on data analysis plans (e.g., approval of study pre-registration documents), interpretation of findings, and how we would put the findings into action (Principles 1 and 4).

The study team worked with the Governance Committee and Youth Advisory group to develop an Indigenous Governance Statement which says how data collected through the study will be used. A specific example of Aboriginal Data Sovereignty in the project was the use of Walkern Katatdjín survey data for the [Rainbow Realities](#) report (Amos et al., 2023). This report brought together data on LGBTQA+ peoples' wellbeing across Australia. The Walkern Katatdjín study team sought permission from the Youth Advisory Group and Governance Committee for survey data to be included in this report so that Aboriginal populations were represented. In these ways, the Walkern Katatdjín study data is owned by Aboriginal and Torres Strait Islander LGBTQA+ community members.



Western Australian Aboriginal Child Health Survey Linked Data Study

The Kids Research Institute

The study builds on the original 2000-02 Western Australian Aboriginal Child Health Survey. Its goal is to generate new knowledge and evidence on the health, wellbeing and life outcomes of Aboriginal children and young people in WA. By connecting to government data, the project makes it possible to look closely at different areas of people's lives, like mental health, education, justice, child protection, disease, and disability.

Funded by a National Health and Medical Research Council Synergy Grant, the study puts Aboriginal leadership and control at the centre. At every stage, from planning to sharing results, the project is co-designed with the community to make sure it has real impact. The scale of community consultation to develop the grant and its research priority areas was immense, involving community organisations across all regions of WA over several years.

The project's research strategy includes five key action areas to make sure it is led by Aboriginal people, follows Aboriginal research standards set by The Kids Research Institute, creates jobs and career pathways for Aboriginal people, has a clear communication plan, shares results with each region, and works with community organisations to help turn the findings into real action.

The project's governance structure includes an Aboriginal Steering Committee made up of senior members of Aboriginal organisations and prominent community members who preside over the study on behalf of all Aboriginal children and families in WA. This committee is supported by a team of 20 Investigators, six of whom are Aboriginal, along with two Aboriginal staff members. All project outputs will include Aboriginal authorship and control over the narrative. The study provides an example of how Aboriginal data sovereignty principles can be achieved when using linked administrative data.



What are we trying to achieve in this study?

Researchers and health services often collect health information from Aboriginal communities. Some of the people collecting this data have knowledge about Aboriginal Data Sovereignty. Some do not. Others have a little bit of knowledge, but they don't know how to put the principles into action. In other words, there's still a gap between knowledge and action.

There is also a gap in knowledge when it comes to mob's preferences and understanding around data sovereignty.

One of the principles of Aboriginal Data Sovereignty calls for us to have access to data that's directly relevant to ourselves and our community. That's why it's important to understand how Aboriginal people in Boorloo would like the principles to be achieved locally.

Through yarning with Aboriginal participants, this project aims to understand community ideas on how to keep Aboriginal health research data safe and ensure the Aboriginal community controls it. Based on the findings of the study, we developed a set of recommendations for researchers, health services and government to support culturally secure data practices and uphold Aboriginal data sovereignty.

What are we trying to achieve in this study?

Aboriginal led, Aboriginal perspectives in research

Shift power to community

Challenge the process

Humility and deep listening

Finding what is meaningful
to Aboriginal people;

Aboriginal ways;

Aboriginal voices,
understanding and listening



The words participants
use are important;

changing participants' words
change their meaning;

Aboriginal perspective
is important

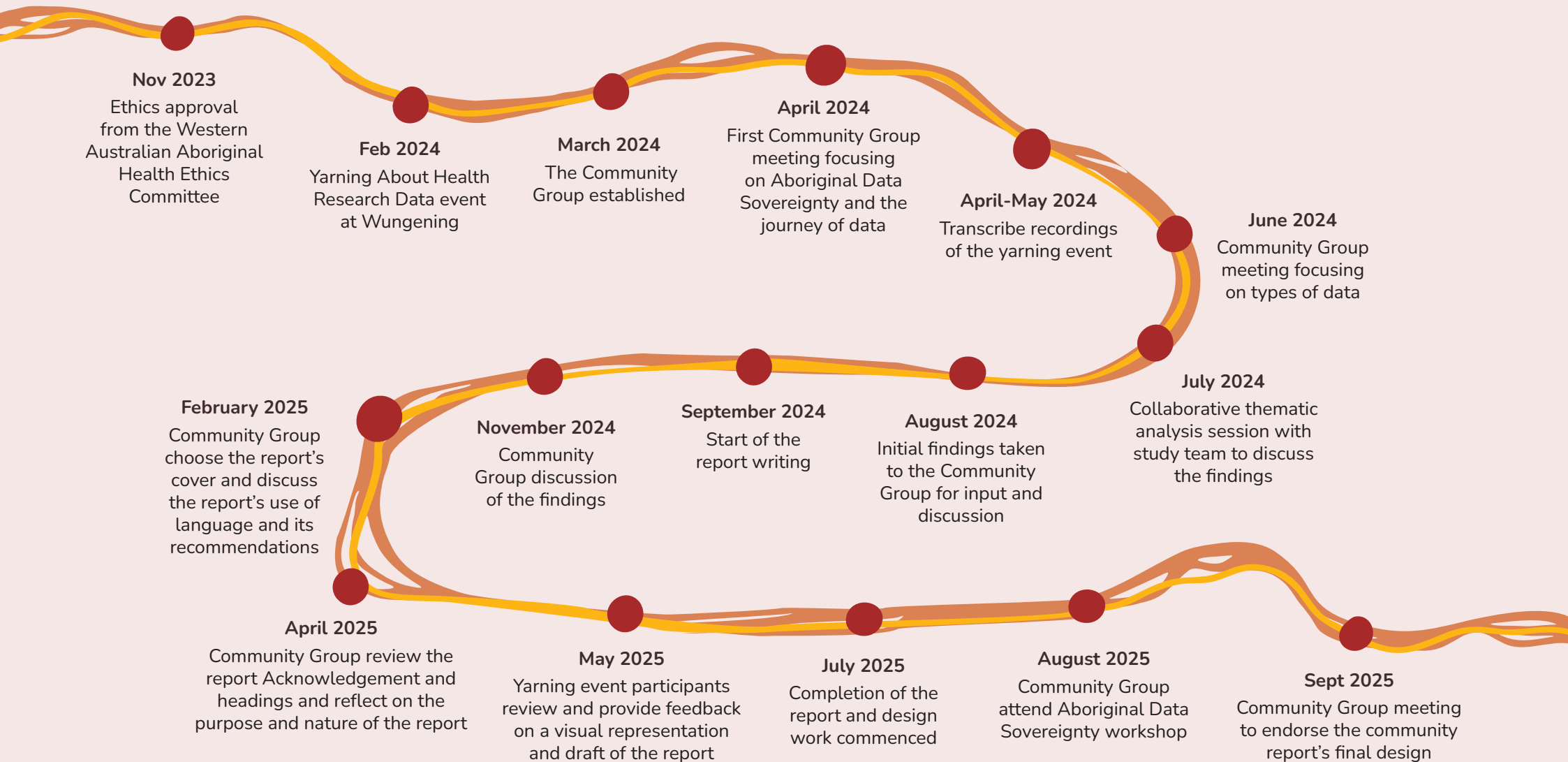
“

*“This report is for the future of our kids.
So we need to get it right to ensure they don't
go through what we are going through now.”*

– COMMUNITY GROUP PARTICIPANT

”

The Study Journey



What we could and couldn't do

Our intention is for the project to benefit Aboriginal people in Boorloo in the area of health research data. However, some ideas and findings are likely to be useful to researchers and health services in other jurisdictions. Our interim recommendations provide researchers and health services with practical ideas on how to implement principles of Aboriginal Data Sovereignty in Boorloo. Our project does not focus on other types of data in areas like the environment or Aboriginal history.

Community ownership and control from the start



In designing this study, it was important to follow the principles of Aboriginal Data Sovereignty.

This meant having Aboriginal people designing the research steps. At the early stages, this consisted of the majority Aboriginal study team. In the leadup to the yarning event, members from Wungening, ECU, The Kids Research Institute, Murdoch and the Consumer and Community Involvement Program met monthly over four months to discuss and plan the event. This process of teamwork allowed for transparency and effective brainstorming.

In these meetings we talked about the following things:

1. Where should the yarning event take place?
2. How will we reach a diverse group (age, gender, location) of Aboriginal community members?
3. How many people should attend?
4. What can we do to make sure that we create a culturally safe space for the yarn to take place?
5. What will we feed participants, and what is the best way to offer reimbursement?
6. What role will the Consumer and Community Involvement Program (a non-Aboriginal organisation) have in the data collection?
7. How will we capture and store all the data?



After receiving ethics approval, we recruited for the yarning event in the following ways:

- Emails and flyers sent through our organisations and networks
- Posts on Wungening's social media accounts and the Facebook pages of The Kids Research Institute and Kulbardi Aboriginal Centre (Murdoch University)
- Phone calls to community members of different ages, genders and places
- Information on the Consumer and Community Involvement Program's website

- Flyers printed and put up on noticeboards at Wungening and Kulbardi Aboriginal Centre.

People registered by contacting Wungening's Coordinator Data Sovereignty who assessed their eligibility, spent time explaining the project and answered any questions. They received follow-up phone calls and email reminders closer to the event date. The reminders included information about parking, transport and location details, along with the participant information letter and consent form.

Wungening has been part of the community since 1988 and has strong connections with local groups. Because they are trusted and well known, they

were in a good position to lead the community engagement for this project. As an Aboriginal organisation, they are focused on creating real change for Aboriginal people and are guided by Aboriginal ways of knowing, being and doing. Their research is not just about collecting information – it's about making their services better and improving outcomes for their clients. They are not part of a big mainstream institution, so they don't let research get in the way of their relationships with the community.

After the community yarning event, community ownership continued through the work of the Community Group.







Ngalla Kaditj Noongar Moort
Keyen Kaadak Nidja Boodja
Ana Moort Yoogoo Kanara
Kabap Moort, Kabap Kaat
Kabap Koort, Kabap Maarak



The Yarning Event

At the yarning event on 21 February 2024, the study team collected information about the community's views on Aboriginal Data Sovereignty and how to keep Aboriginal health research safe. Guided by Elders from Wungening, we wanted the event to showcase how data collection can be done differently and respectfully, through Aboriginal ways.

We aimed to recruit 30 Aboriginal participants for the yarning event. They had to be over the age of 18, living in Boorloo and able to give informed consent to participate. Because we wanted to understand the views of the general Aboriginal community, we excluded participants working in health research, as they may have had previous training in Aboriginal Data Sovereignty.

"I felt comfortable. I didn't know anyone at the table, but I felt comfortable."

We held the event after hours at Wungening's office in Royal Street, East Perth. East Perth is a place of cultural and spiritual significance to the Whadjuk Noongar people – it is a stone's throw from Moort-ak Waadiny (Wellington Square) and Derbarl Yerrigan (Swan River). Before colonisation, Noongar people met, lived, played, foraged, fished and hunted in the area.

The yarning event was led by yorga (woman) Elders from Wungening: the Cultural Capital Officer and Culture and Healing Practice Lead. Through collaboration, they conceived and delivered most of the cultural safety concepts behind the yarning event, including the healing and hospitality rituals, extensive use of paperbark art, the tables representing the six seasons, and the curation of sound. Assisted by Wungening's Coordinator Data Sovereignty, they ensured the evening was memorable and culturally safe.

At the Wungening entrance, participants engaged in a Spiritual Healing ritual. An Elder invited them to cleanse, heal and connect to Country by placing their hands in water and sand from Derbarl Yerrigan, followed by holding their hands up to the sun. The sun represents warmth, energy and resilience.

After entering the large foyer, participants encountered a bush theme, while a recording of bird sounds from the south-west played in the background. The study team invited participants to have kangaroo stew and hot drinks. The foyer held six round tables, which were covered with different coloured tablecloths representing the six Noongar seasons.

Yarning is an important part of Noongar culture, which is why it became our way of collecting information. The team recreated a campfire-style of gathering around a yarning circle. In the middle of each table was a collection of rocks and pieces of bark around a battery-operated candle representing a campfire. There were also native flowers and a talking stick. The Noongar language also played an important role. Each table had a handwritten Noongar welcome to country and the name of the season on paperbark.

These carefully designed cultural elements made the yarning event unique in the research space and displayed the truly Aboriginal-led nature of the research. Since the evening was ambitious and experimental in nature, we were keen to receive feedback on how to improve future events. In follow-up phone calls, participants told us their experiences of the evening:

- "The setting was culturally appropriate and welcoming."
- "I felt comfortable. I didn't know anyone at the table, but I felt comfortable."
- "I had never discussed that before in my life until that night. Never really thought about data before – it's something way overdue."

Most of the feedback for improvement was about practicalities such as the size and sound quality of the foyer for the large number of participants recruited.

What did we do at the yarning event and why?

In being true to Aboriginal Data Sovereignty, we wanted to base our actions on a respectful relationship with mob. Our relationship had to be more than about consultation: we needed to properly engage. Just as we hoped the report would help support the community's self-determination, we also wanted the process of creating the report to empower participants.

Thirty-two participants took part in the yarning event. After signing the photo and participant consent forms, they sat at one of the six tables representing the six Noongar seasons. We did not take any demographic information, but they ranged from people in their twenties to Elders.

At the start of the 2.5-hour yarning event, members of the study team introduced the study and instructions for the evening's activities. Each table had an Aboriginal facilitator from the study team who asked the questions, and a scribe wrote down key discussion points on butcher's paper. We also audio recorded the yarning at each table.

The facilitators asked the following questions relating to Aboriginal Data Sovereignty:

1. Thinking about health research, how do you define 'data'? Please share some ideas of what specific personal health information you consider to be 'data'.

2. What, if anything, do you know about the current ways that researchers make sure that they collect and use Aboriginal and Torres Strait Islander health data in a safe and respectful way?
3. What are some ways that researchers can protect Aboriginal and Torres Strait Islander peoples' health data?

At discussion time, the groups yarned about the three questions, with a half hour break for dinner. Each table had a talking stick, which was used by those who chose to. The session wrapped up with a large group discussion to summarise the table discussions.





Ngalla Kaditj Noongar Moort
Keyen Kaadlak Nidja Boodja
Ana Moort Yooqoo Kanana
Kabap Moort Kabap Kaat
Kabap Koort Kabap Maarak

Making meaning of the stories

The work of analysing and understanding the participant stories happened over several months and stages. In keeping with the principles of Aboriginal Data Sovereignty, we continued to involve participants after the yarning session. Through a series of follow-up yarning events, the Community Group discussed visualisations of the report's contents. We later offered all participants the opportunity to provide feedback on a draft of the report. Their feedback and advice influenced findings, recommendations and the final copy of the report.

1.

The team collected the recordings and notes to transcribe them at Wungening.

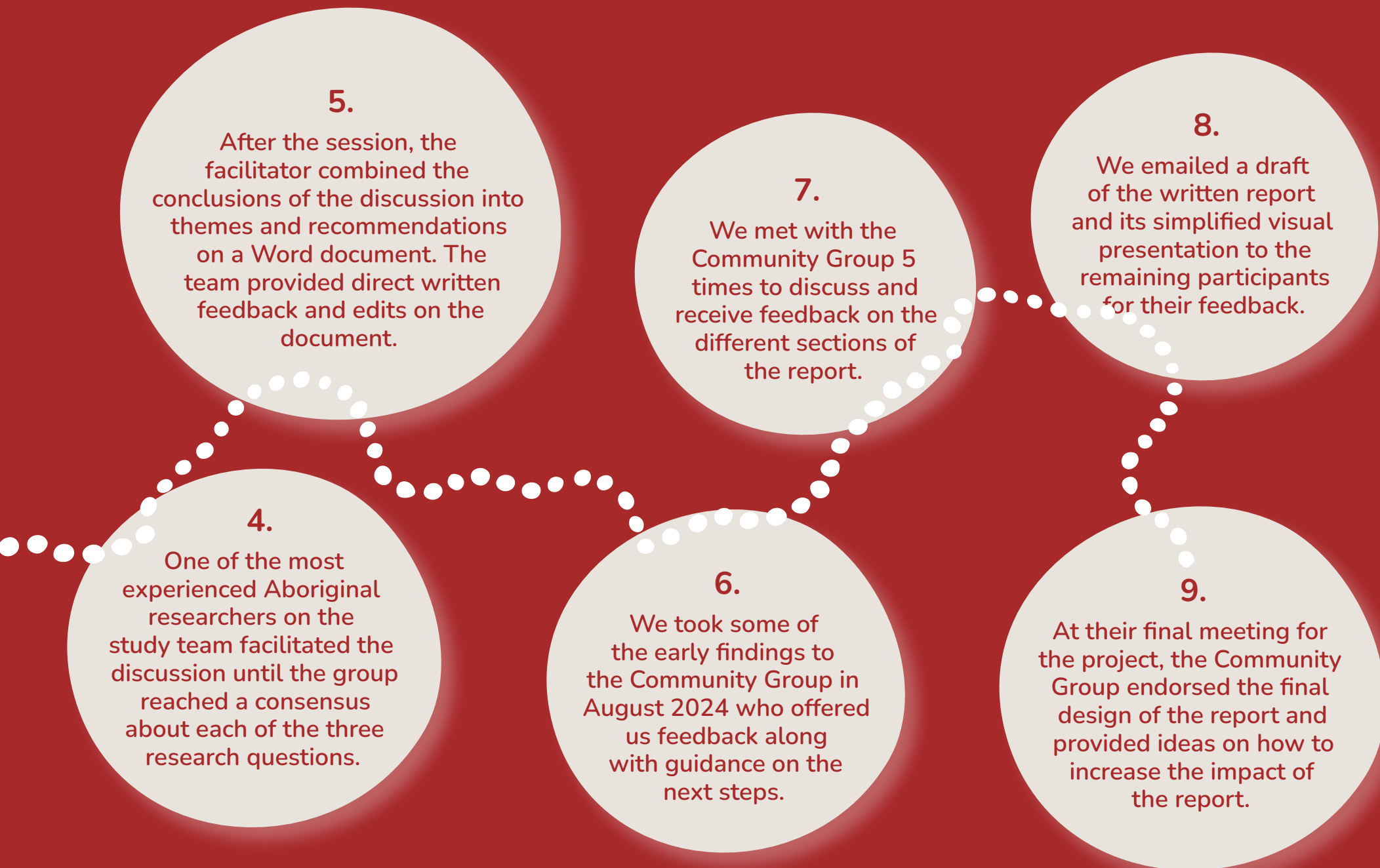
As a team, we decided not to use software like NVivo to organise the information. Instead, we gathered members of the study team for an in-person yarning session in July 2024 to discuss the main themes of the stories.

2.

At the session, the team looked over the transcripts and participated in a collaborative thematic analysis where each member had a chance to present their understanding and interpretation of the transcripts.

3.

Working collaboratively allowed for the team to moderate personal biases while still letting lived experience inform the analysis and develop a nuanced shared understanding of the data.





How did we work together on this project?

Existing literature or guides usually focus on how non-Aboriginal researchers or organisations might work with Aboriginal participants or community-controlled organisations (Bennett & Gillieatt, 2022).

But we hear very little about the strengths that can be found in the partnership between Aboriginal researchers and Aboriginal community-controlled organisations. A project like this succeeds or falters because of its partnerships.

As a community organisation, Wungening has been involved in over 20 research partnerships in the past four years. While some of these have been positive and collaborative, many have reflected long-standing power imbalances in the research space. Too often, research and evaluation projects are shaped by non-Aboriginal agendas – driven by external funding requirements, led by non-Aboriginal researchers, and framed around outcomes that do not reflect what matters to the Aboriginal community. These experiences have, at times, been disempowering and have perpetuated colonial patterns of knowledge extraction, where Aboriginal voices are marginalised, and data is used in ways that do not lead to meaningful change. Wungening's involvement in these processes has highlighted the urgent need for research to be reimaged as something that empowers

community, centres Aboriginal knowledge systems and is accountable to the people it claims to serve.

Aboriginal Data Sovereignty is about respecting the rights of Aboriginal people when it comes to their data. All research partners on this project are committed to the principles of Aboriginal Data Sovereignty, and this has had a positive impact on our partnership. We knew we could trust each other because we had a shared goal, to place the social and emotional wellbeing of Aboriginal people at the heart of what we do.

What made this partnership fearless was our shared commitment to safety and mutual respect, and our readiness to challenge not just institutional norms, but also our own assumptions about how research should be done. Being fearless meant acknowledging when things weren't working and being bold enough to make changes. Together, we adjusted our approach to meet the needs of the community, even when that meant going against the usual 'rules' or throwing out our original timeline to ensure genuine community involvement. It also meant supporting

each other through the anxieties that came with stepping away from academic traditions, like choosing not to write a formal academic report. Instead, we created a community report because participants and the Community Group told us it was important that the research be accessible and owned by community.

Wungening's "Partnerships: Statement of Respect for Aboriginal Knowledge, Information, Culture and Data" is a document that Wungening sends to its research partners. The document affirms Wungening's goal to "work with collaborators, including funders, consultants, service providers and researchers, in positive, progressive ways which value and respect the importance of Aboriginal knowledge and intellectual contribution." Similarly, The Kids Research Institute's *Guidelines for the Standards for the Conduct of Aboriginal Health Research* is designed so that the Institute's research on the health and wellbeing of Aboriginal communities is conducted by and with them, "in a way that ensures the knowledge generated by that research stays with communities."



The study team at Wungening, ECU, Murdoch, and The Kids Research Institute had an existing relationship, and given that we hold the same views about Aboriginal Data Sovereignty, entering a study partnership was an easy choice to make. Additionally, the invitation for Wungening to be the lead partner demonstrates a commitment to ensuring the research would be led and owned by the Aboriginal community, since an Aboriginal community-controlled organisation would have control of the data on behalf of the community. The partnership with the Consumer and Community Involvement Program was new, and it was also intended to be comparatively shorter. Their role revolved around assisting with the yarning event, particularly with scribing the main notes of conversation at each table. This represents a different role to what the Consumer and Community Involvement Program staff usually hold when they run community conversations with other groups. Typically, the program staff would lead the conversations; however, in this project, the Aboriginal team members led the conversations with participants.

Partner reflections of working on the project

Wungening

The Wungening team are so grateful to have developed skills we learned from our partners throughout the project. For example, we developed our capacity from the study team's established Aboriginal scholars who facilitated the data analysis session in July 2024. The session started with the question of what the key themes were for each of us. From there, the conversation flowed, until the group reached a consensus about each of the three research questions. Wungening appreciated this style of facilitation and way of analysing data, which privileged Aboriginal perspectives and helped to ensure all team members present had a say. It also allowed for members new to research to participate meaningfully in the session. We learned not to take away from the voice of participants by overlaying it with our own experience or assumptions, even if our perspectives were congruent or sympathetic.

The Wungening team was able to lead and learn because the partnership felt safe and supportive. Our partners helped us build our skills and confidence in a respectful and encouraging way. They gave us space to recognise our own strengths and grow from them, rather than being driven by a fear of getting things wrong. At every stage, our partners focused on what the Wungening team brought to the work and they valued the strengths we had.

Wungening has been strong in calling for change in how research and evaluation is done, and we look for partners who are willing to do things differently, too. For us, an authentic and fearless partnership means open communication, respect and being willing to learn and change along the way. That's what we experienced with our academic partners in this project. We appreciated being genuinely valued in the partnership and trusted to lead the project in ways that reflected the needs, voices and strengths of the Aboriginal community.

ECU and The Kids Research Institute

We were struck by how Wungening set up the event to feel like Country and be welcoming for everyone. This demonstrates the importance of working with cultural knowledge holders, and what we can achieve when cultural safety is the number one priority. Even as a Noongar woman and researcher (Bep) who has yarning circles as part of research projects, I had never thought of setting up the physical space of a yarning circle to be so authentic. I learned a lot from the Wungening team and Elders' suggestions about breathing cultural safety into the event. I believe this made the event a unique way to discuss data sovereignty – a way that truly privileged our ways of being and doing. As a Wajarri young person (Shak) this showed me the importance of slowing down to listen to Elders and keeping the research grounded to the Country we were on.

We also appreciated how Wungening were able to reach out to community that they have existing relationships with and yarn properly about the project, well before data collection started. This was a fantastic way of ensuring that participants gave their free prior and informed consent to take part in the project. It also shows that, as an Aboriginal community-controlled organisation, Wungening has been able to build real relationships with community that extend into their research, instead of being transactional.

Even as Aboriginal researchers, we have been trained in Western institutions and sometimes get used to doing things 'the usual way'. This project has shown how much we still have to learn and how much community research is strengthened when led by Aboriginal community-controlled organisations.

Kulunga Aboriginal Unit (The Kids Research Institute)

It has been a great privilege to participate in this project. Seeing an Aboriginal-led organisation bring us together and collaborate for the benefit of communities has been amazing. It builds on work that The Kids Research Institute is undertaking with the implementation of Aboriginal Standards and embedding Indigenous Data Sovereignty principles. The yarning event evening was memorable for so many reasons. Wungening Elders made the night very special, and the careful planning and execution that went into it showed throughout the evening. There was culture, community, voices, learnings and respect in the room. The ongoing consultations with our community have been important to ensure research is done on our terms and also highlights that we as research/health practitioners need to listen more to our mob. There is so much wisdom, lived experience and insightfulness that without it, it isn't truly best practice in research and won't get the meaningful benefits for Aboriginal families that we envisage.

Consumer and Community Involvement Program Team

Being involved in the yarning event with participants was a true privilege for our team. It was an enlightening experience that contrasted with our more familiar role, where we facilitate and lead the conversations. In this instance, we had the honour of playing a supporting role, scribing and capturing the process, while Aboriginal researchers led the conversations with the community. We were deeply moved by how culturally immersive the event was, from the welcoming ritual to the carefully crafted yarning space that reflected the essence of Country. The visual impact of culturally safe materials on the tables, such as the Noongar language and symbols, made us realise how much can be gained by integrating cultural identity into every aspect of the event. Walking away from the experience, we gained many insights – especially in understanding how we can engage alongside communities in a way that is respectful, supportive and grounded in cultural safety. This event has broadened our perspective on the vital role of cultural knowledge and community-led processes in research.



What we heard

Participants spoke about the importance of having their personal stories heard, respected and honoured in the collection of health data. This is why we have chosen to include their words as much as possible in the next section.

What did the community have to say about health research data and Aboriginal Data Sovereignty? Key take-home messages

- 1. The term 'data' needs to be redefined or broadened**
 - Some participants saw data as a clinical term that does not capture the richness of people's lives, including their trauma and the contexts in which they exist.
 - Aboriginal people view both their stories and histories as data.
 - There was a preference for providing a human focus to data by listening to people's stories.
- 2. Health research and health service data are seen as the same thing**
 - Although our project focused on data collected through health research, participants did not view health research data as separate from the broader health data that services collect for healthcare provision. Health data also encompassed information included in referrals to services.
- 3. There is uncertainty about current practices for keeping Aboriginal health data safe: Why is this data being collected? Where does it go? Who does it benefit?**
 - Participants noted that there should be more clarity around where health data 'goes' once they have provided it to a service. For example, when accessing a health service or setting up an employment record, what does 'ticking the box' that you are Aboriginal and/or Torres Strait Islander mean in terms of how your information is used?

4. Participant concerns over data access

- Participants found it difficult to access adequate or complete government records, such as those relating to the Department of Native Welfare.
- Participants talked about how data can provide important history, so losing or not being able to access the data means a loss of stories and their ownership. Most families, even those not directly impacted by Stolen Generations, still face this issue.
- While participants expressed concern over privacy issues, there was also a call for health data, just like family history, to be available for the benefit of family members and future generations.
- There is a lack of transparency about how and where Aboriginal health data is stored and who can access it.
- Participants did not know whether or how to access the reports or publications to which their data has contributed.
- Participants expressed a need for clarity over who can access Aboriginal health data. This need also relates to concerns around the privacy and confidentiality of health service data and concerns about extended family members seeing health records if they work in a health service.

5. Participant concerns around current practices for collecting and storing data

- Some participants believed that researchers and services collect health data primarily for funding purposes with minimal benefit to the people and communities whose data is collected.
- Some participants described events in health services where their health data had been mixed up with someone else's, resulting in either scepticism over patient confidentiality or concern over harmful practices.
- There is a need for more clarity and transparency over data storage, reuse and access policies and practices.
- Lack of communication by researchers led to feelings of mistrust and wariness among some participants.
- There is a potential for participants to be re-traumatised through data collection practices.
- Researchers think they own the data, but participants believed the community should by rights own the data.

- There was concern over how data is collected, the conclusions researchers reached and the limited amount of information that participants receive, which reflect the power imbalances of colonising practices.
- Participants spoke of a lack of informed consent when using health services and participating in research.
- There were fears of negative (that is, deficit) data being put into systems without the context of someone's circumstances, and therefore potentially leading to harm, for example, child removal.
- Participants expressed concerns over data potentially being used in ways that participants did not initially consent to.
- Some participants expressed concerns about how data is collected, and what kind of data is collected, including the possibility of DNA data being collected and how that might be used.



6. There are ways that researchers and services can collect and keep Aboriginal health research data safe

- Collect data in a relational, not transactional, manner. In other words, prioritise people first, not numbers.
- Ideas about achieving the principles of Aboriginal Data Sovereignty are present in Aboriginal communities, but researchers and health services need to listen to them.
- Health data and data collection practices should reflect the fact that health is holistic.
- Care should be taken for people's wellbeing when they access their data. For example, when reviewing difficult health data records or child protection records, people should have counselling support.
- People should be able to review the data that they contribute to a research project.
- Many participants indicated that there should be one central place to store Aboriginal health data.

7. Consider the contexts surrounding the collection of Aboriginal health research data

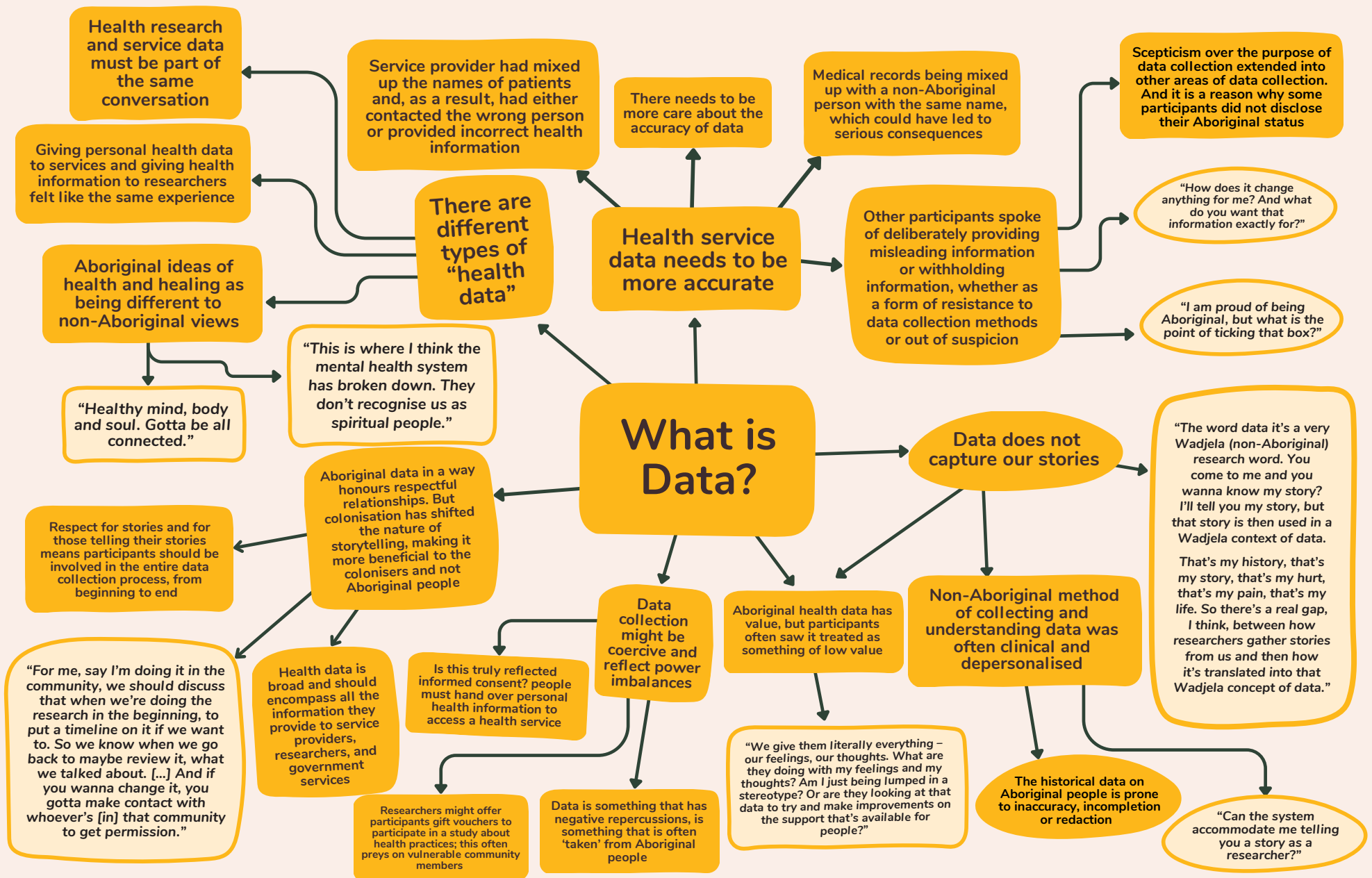
- The ongoing impacts of colonisation meant that discussions about Aboriginal Data Sovereignty and health research occurred within the context of colonisation.
- There are possible generational differences in which there might be more trust for researchers among younger generations, as data practices improve and data literacy increases.
- Participants said that many community members provide health data within a context of fear, scepticism and disempowerment.

We discuss each of these points in further detail in the following analyses.

The definition of 'data' in relation to health research

We wanted to understand what data meant to participants. During the collaborative thematic analysis session, we discussed participants' responses to this question by considering the following:

1. What were the types of health data that participants discussed?
2. What definitions of health data did participants provide?
3. Was there overall agreement or disagreement between participants and their definitions of what counts as data?
4. Were participants' descriptions of health data consistent or different from how researchers define it?



The types and definitions of health data that participants discussed

Health research and service data must be part of the same conversation.

This research specifically focused on health data collected as part of research projects (that is, health research data). However, we realised that participants did not usually make a distinction between health research data and the health service data that services routinely collect to enable people access to health care. In fact, when we asked them to define health research data, most participants discussed health service data.

Participants listed the following sources of health data:

GP records

Records from Aboriginal health services

Medication prescriptions

Referrals to specialist health services

Blood test results, including the heel prick test that babies get at birth

Medical photos

MyGov records (for example, Medicare records)

Personal health information collected by health services for funding submissions (for example, through surveys)

Personal health information collected by researchers for studies (for example, through interviews)

More broadly, participants mentioned the following sources of data and how these might be linked to a network of health data:

Library records (for example, Battye Library)

Ancestral and native welfare records (for example, from the National Archives, Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and Department of Native Welfare)

Oral histories and traditions

Data held by Centrelink

National census data

Criminal justice records



Although it wasn't explicitly stated, participants' discussions suggested that giving personal health data to services and giving their health information to researchers felt like the same experience. In short, they viewed health research data as just another form of health data.

Similarly, several participants spoke of Aboriginal ideas of health and healing as being different to non-Aboriginal views. The implication is for a broader definition of health data, one that includes what is meaningful to Aboriginal people.

"This is where I think the mental health system has broken down. They don't recognise us as spiritual people. There needs to be. Cos we got a spiritual connection in our DNA. They should [be] culturally appropriate in spirituality."

"So, the only thing that was healing [my dad] was the fire in our backyard. We always had a fire. [...] So, the fire was much, much better to him than medication. And a wholesome, strong stew and meat."

"Healthy mind, body and soul. Gotta be all connected."

Inaccurate health data.

Participants said that health service data needs to be more accurate. For example, participants from each of the yarning circle tables recalled instances where a service provider had mixed up the names of patients (often because Aboriginal family members have the same names across generations) and, as a result, had either contacted the wrong person or provided incorrect health information. There was a general sense that, whether in research or health services, there needed to be more care about the accuracy of data.

"They pulled up [my medical records] one day and said, 'Which [name] are you? We got four of you.' And I said, 'I must be the oldest, surely.'"

"At the moment, we've got a service that's in Perth, a non-Aboriginal service, and they have Aboriginal women's groups and they're collecting extensive data around medical history, blood sugar levels. And they're not taking the blood sugar levels themselves. They're asking the clients to fill out this information, and it's extensive. It's like, have you got osteoarthritis? And most Elders wouldn't think, they don't think, they're just ticking away. And when I looked at it, I was like, hang on, this is asking if you've had pancreatic cancer, if you've had all these different [illnesses], but it's for their funding."

In one example, a participant spoke about her medical records being mixed up with those of a non-Aboriginal person of the same name, which could have led to serious consequences.

“When I went down there, they seen that I was black. This was a Wadjela (non-Aboriginal person). So, they just mixing them up. [...] She was an addict and she was using and all that. They said what I had. No, I don’t have that. I’ll have a blood test, ya know? [Laughter at the table.] And me and my man started arguing because I was, you know, saying, well you must have gave me that. I’ve gotta go and have a look, you know what I mean? But then they said, oh no, it’s not you – the other woman was white. But they got the information. Oh yeah, it’s [full name], here we go, ring her up and give her this bad diagnosis.” [Laughs.]

Other participants spoke of deliberately providing misleading information or withholding information, either as resistance to a researcher’s methods or out of suspicion and mistrust.

“Also, when you get researchers calling you out of the blue. I don’t know if doctors are flagging you on their system, and it’s like, how did you get my number? I didn’t give you my number. Who are you? [...] I come in, and she says, ‘It’s liver research,’ right? Oh yeah. [...] You know what? I fed her a whole lot of bullshit.”

“I get too scared to share too much data because I am sitting there going, ‘What do you want with that information? What are you gunna do?’ And sometimes, so I just don’t.”

This scepticism extended into other areas of data collection. It is a reason why some participants did not disclose their Aboriginal status or were highly reluctant about disclosing it.

“I am proud of being Aboriginal, but what is the point of ticking that box? It’s not going to change who we are as people, whether we’re human or not. Like why do we even tick that box?”

“I felt the same recently when I had a hospital stay. I had to say to them, ‘What does it matter to me? You don’t care. How does it change anything? How does it change anything for me? And what do you want that information exactly for?’”



Was there overall agreement or disagreement between participants and their definitions of what counts as data?

Overall, the discussion took in several discussion points, with participants being critical of what often counts as data. Participants essentially agreed that the current collection and definitions of data have their limitations, especially from an Aboriginal perspective.

Data does not capture our stories.

Another finding from participant discussions is that stories are data. As one participant said:

“I think that data to us means stories.”

Participants wanted researchers and health services to hear their whole story in the context of their lives. A single clinical data point does not do justice to their full story and humanity. Participants suggested that research methods should allow researchers to capture and honour people's full stories.

“The other issue I have about the word ‘data’ is it’s a very Wadjela (non-Aboriginal) research word. If you want me to talk to you on a research project, [if] I’m on a research project for you as a participant, you come to me and you wanna know my story? I’ll tell you my story, but that story is then used in a Wadjela context of data. That’s my history, that’s my story, that’s my hurt, that’s my pain, that’s my life. [...] So there’s a real gap, I think, between how researchers gather stories from us and then how it’s translated into that Wadjela concept of data.”

Participants believed the non-Aboriginal method of collecting and understanding data was often clinical and depersonalised: as a participant said, “It’s very clinical – cold sort of.”

Though researchers might be resistant because of their training and methods, they should instead consider stories as a valid form of data.

“Can the system accommodate me telling you a story, as a researcher?”

What's more, participants believed the historical data on Aboriginal people is prone to inaccuracy, incompleteness or redaction.

“But I also saw in [my family Native Welfare records], they reckon they gave all the historical facts, the stuff they wrote about my mum and grandfather, and there was a lot of stuff that was blacked out. And I was like they obviously read it, but they didn’t think it was for me, a family member that wanted to have a bit of history. Data’s a funny thing.”

Aboriginal health data has value, but participants often saw it treated as something of low value.

This negative perception of how researchers or services manage Aboriginal data fed into fears of what might happen to a person's information and how it will be interpreted and presented, and if it will harm more than heal.

“For me personally I have had to have a lot of dealings with doctors for myself and my children, and I am always worried about a lot of things that we have to give. We give them literally everything – our feelings, our thoughts. What are they doing with my feelings and my thoughts? Am I just being lumped in a stereotype? Or are they looking at that data to try and make improvements on the support that's available for people?”

“All these heritage surveys that happen around the place, Noongars are out there telling their stories – stories that have been handed down from the old fellas and they're getting paid like \$650 for a day. I mean there's gotta be value in that. I think it's a bit more than \$650.”

Even so, some participants understood the economic value of their stories in a number of contexts.

In relation to health research, one participant talked about teaching Elders to know their power by giving out information only if they received payment.

“Those Elders that I was talking about, one of the lessons I think is, we've now got researchers lining up at the door, which now works for them, the Elders, but only cos they know. I kept saying to them, don't give your story for free. And even when they start saying where they're from, I stop them and say, uh-uh, that's worth money – stop now, and we'll organise a payment for you first.”

For participants, Aboriginal data has worth beyond what researchers attribute. They believe that researchers should consider the true worth of Aboriginal data/stories.

Data collection might be coercive and reflect power imbalances.

Participants recognised that data can lead to negative repercussions. As something often 'taken' from Aboriginal people, data collection can be coercive, reflecting a power imbalance between researcher and participant. For example, researchers might offer participants gift vouchers to participate in a study about health practices. But this practice often preys on vulnerable community members, making the small financial incentive the primary motivator to take part in a study.

“They were just ringing me up and they giving me a voucher. [...] They used to ring me up every couple of months and give me a \$25 voucher or something like that [laughs].

Well they giving me vouchers and then so I'm just like, OK, well I'll give you some information. [...] I just want that voucher.”

“Historically we've had to tell our stories to authorities. We've had to disclose. We've had to, you know, put our necks on the line. Like, our parents did, and we all did. We've had to do it. That's what saved us a lot of times. We were never given an opportunity to be given a voice.”

Participants questioned whether the practice of providing vouchers to vulnerable groups truly reflected informed consent. Likewise, people must hand over personal health information to access a health service or provide consent to terms and conditions they don't fully understand to receive a service. Participants felt these ways of working were transactional at best or coercive at worst. An example of a voluntary test that has created confusion and distress over bodily rights is the Guthrie or heel prick test, which screens infants for rare genetic conditions.

“What is that about? I still don't know, even though I have four kids and stuff. I just expect that, ok, if there's something wrong, they're gonna –”

“Where does it go?”

“Who explains that? That's our sovereignty. My right, your right, as a mother, to have that done or not. I get that might be for a good reason. I understand that. But who is explaining it?”

One participant noted that power imbalances can be found in who collects data, controls it, uses it and generates funding – especially if the community providing the data sees little benefit, if at all. The participant gave an example of how a researcher published findings that resulted in misrepresentation of a community, which could have been avoided if the study team had checked their understanding of the findings with participants.

“So that they can get funding. That's what it all goes back to. From my own experience, I've noticed it goes back to doing a funding submission and going, oh, we've got this much stats so this can affect women's whatever. So that they can get their funding. But at the end of the day, our clients or the community, they don't actually get a say in that, and they don't know. They've been tagged with, ‘This community has a higher percentage of women with ovarian problems.’ They have no idea it's their community. So it's a bit of a worry. Ten women out of 500 are living in the area. Ten women have answered a survey for a \$30 gift card. I've seen it way too many times.”

Data collection in a relational framework is possible.

Some participants emphasised the collection of Aboriginal data in a way that honours respectful relationships. But colonisation has shifted the nature of storytelling, making it more beneficial to the colonisers than Aboriginal people. The participant who told us that “Historically we've had to tell our stories to authorities,” also said:

“I see [Aboriginal Data Sovereignty] as relational. Sometimes this stuff is transactional. And there's a big difference in if you're doing a transaction versus developing relational sort of quality sharing, if you know what I mean.”

Respect for stories and for those telling their stories means participants should be involved in the entire data collection process, from beginning to end. It also includes mutually agreeing to the purpose for collecting data and only using the data for that purpose, unless further permission was granted.

“For me, say I’m doing it in the community, we should discuss that when we’re doing the research in the beginning, to put a timeline on it if we want to. So we know when we go back to maybe review it, what we talked about. So it could be that way. And if you wanna change it, you gotta make contact with whoever’s [in] that community to get permission.”

Was there overall agreement between participants about what counts as data? Were participants’ descriptions of health data consistent or different from how researchers would define it?

As we have seen, participants agreed that health data is broad and should encompass all the information they provide to service providers, researchers and government services (for example, Medicare). This definition of health data is much broader than the definition of health research data that we originally held as a study team.

Knowledge about how researchers make sure they collect and use Aboriginal health research data in a safe and respectful way

Our next question focused on community’s understanding and experiences of how researchers and services collecting health data in Boorloo uphold principles of Aboriginal Data Sovereignty. The following questions guided our analysis:

1. What current practices for keeping health data safe did participants give examples of? (if any)
2. Was there a consensus that researchers and organisations keep Aboriginal health data safe?
3. What were participants’ understandings of the term Aboriginal Data Sovereignty?
4. To what extent were participants aware of current research guidelines for keeping Aboriginal data safe? If aware, did they believe these were effective?



What current practices for keeping health data safe did participants give examples of? (if any)

A small number of participants gave **examples of what they considered good data practices.**

As a bare minimum, good data practice meant only using their data for the things that participants had consented to, as one Aboriginal health service in Boorloo had done.

Participants were also enthusiastic about research that was done by Aboriginal researchers who had built relationships with community. This way of researching enhanced trust and transparency around data practices.

“It’s so good to know that Aboriginal researchers are now taking a front line on this stuff around questioning and finding out that data because I think they can build that rapport quicker.”

They were also interested in the role ethics committees have as safeguards for research and data, although participants did not know what level of accountability this offered. Some of the actions participants had for ethics committees (for example, asking researchers about Aboriginal Data Sovereignty) are currently being done.

“...all research has to pass ethics, I’m just wondering whether there is any consideration about including data sovereignty processes into an ethics application.”

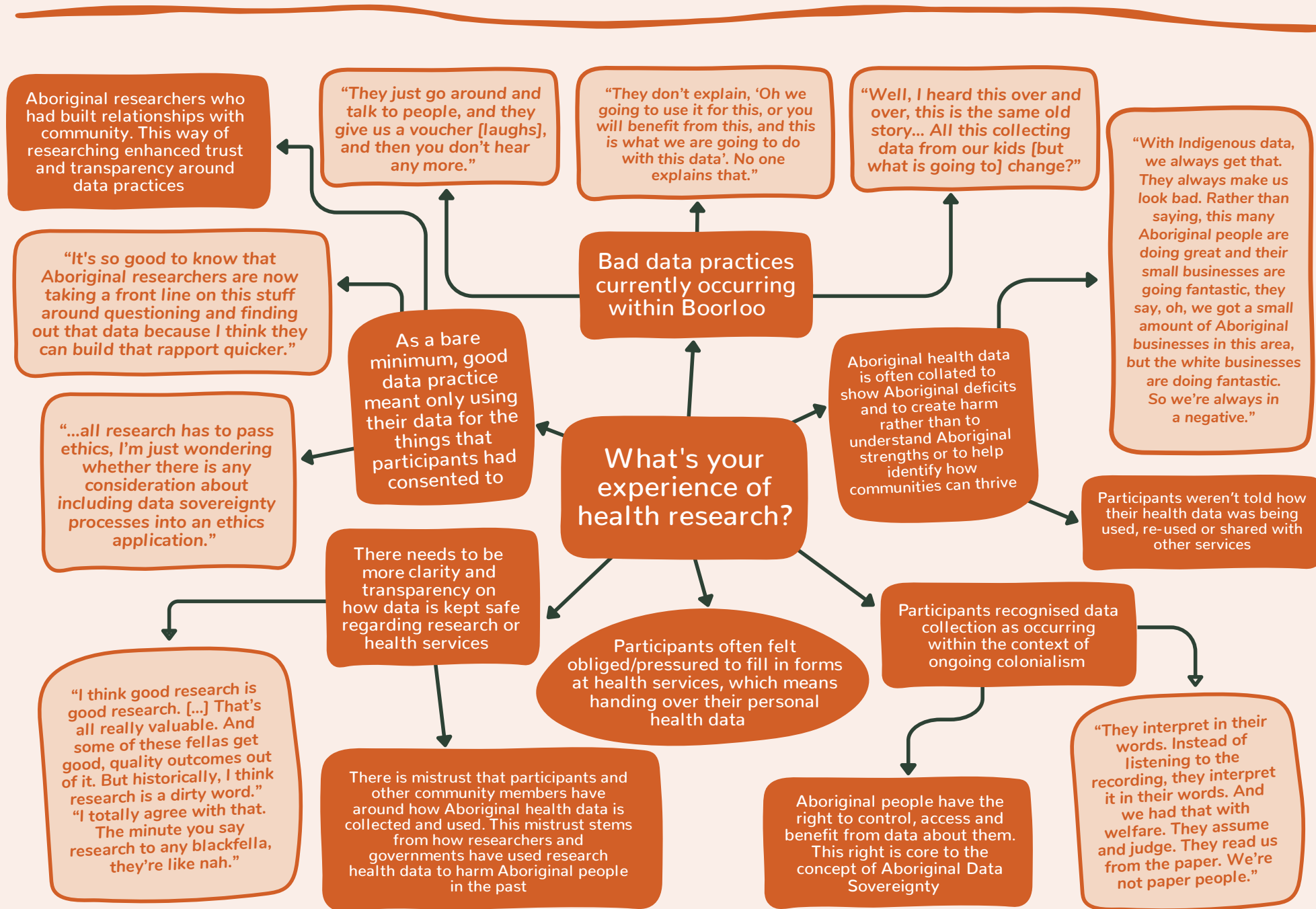
Participants encouraged critical self-reflection among researchers and had been prompting researchers to reflect on their personal and professional reasons for collecting and using data.

“But also explaining that they really [need to understand] why they’re asking those questions.... Why are they actually doing this research?....What is it that you are trying to accomplish? And do you really know why you’re collecting this data? Do you really know why? I don’t think any of us that’s ever been questioned have asked that question to the researcher: Why?”

It should also be noted that whether health data storage is considered ‘safe’ depends on the individual and their access to information about relevant data practices. For example, a health service may think they are keeping data safe by following patient privacy guidelines. But if these guidelines and expectations are not known by the patient then the patient may feel their data is unsafe. Many participants do not know what happens to the data they hand over.

Most participants gave **examples of bad data practices** currently occurring within Boorloo. They had often been involved in some portion of the data collection of a research study but had not seen the end goal of the research.

“They just go around and talk to people, and they give us a voucher [laughs], and then you don’t hear any more.”



Researchers were also not making it clear to participants about why data was being collected and where it was going.

“They don’t explain: ‘Oh we are going to use it for this, or you will benefit from this, and this is what we are going to do with this data.’ No one explains that.”

On a similar note, participants expressed concern that Aboriginal health data was being collected with very little benefit to community. Participants also felt frustrated at repeatedly providing the same data for various projects.

“Well, I heard this over and over, this is the same old story... All this collecting data from our kids [but what is going to] change?”

“There is a lot of research that has been done for a long time. What is all that going towards? And how is that gonna benefit not just myself but future generations?”

“They all seem to be researching the same thing.... Are they trying to outdo each other?”

Additionally, participants said that researchers did not prioritise data that shows Aboriginal strengths (what we call ‘positive data’). Participants observed that Aboriginal health data is often collected to show Aboriginal deficits and to create harm (for example, collating data on families for child removal) rather than to understand Aboriginal strengths or to help identify how communities can thrive. This is similar to what Maïam nayri Wingara and other Aboriginal researchers have to say about ‘deficit data’ versus Aboriginal people’s data needs (Walter, 2018).

“Rather than saying, ‘This many Aboriginal people are doing great and their small businesses are going fantastic,’ they say, ‘Oh, we got a small amount of Aboriginal businesses in this area, but the white businesses are doing fantastic.’ So we’re always in a negative.”

“With Indigenous data, we always get that. They always make us look bad.”

Participants weren’t told how their health data was being used, re-used or shared with other services. For example, one participant discussed how they received an unsolicited phone call from a researcher.

“I’m diabetic, and I’ve given all that information over, next thing you know I’m getting calls about diabetes. I’m not even telling them. I don’t know who they’re giving it to.”

In essence, participants generally did not know how services are set up to protect their health data.

What were participants' understandings of the term Aboriginal Data Sovereignty?

Most participants did not know the term Aboriginal Data Sovereignty, and it is not a term they had heard researchers use. However, participants understood the principles behind it. Participants' comments reflected an understanding of:

- Aboriginal peoples' right to custodianship of their data
- the need for Aboriginal data to be analysed by Aboriginal people
- the deficit or negative approach often taken in research on Aboriginal people versus Aboriginal people's need for positive and contextualised data
- the potential negative impacts of data collection on community.

Overarchingly, participants recognised data collection as occurring within the context of ongoing colonialism.

“They interpret in their words. Instead of listening to the recording, they interpret it in their words. And we had that with welfare. They assume and judge. They read us from the paper. We’re not paper people.”

“If you want to put our kids in care, then any data collected from that family or from those children needs to be communicated to them. Needs to go to their profile. They do it for, like, if you get arrested, you automatically have a profile. It sends it to Centrelink, tax office – they’re all connected. So how it is for that child’s safety and care, how is their data linked to their medical history?”

“Comes back to the UN and the Human Rights Charter [Declaration of Human Rights]. Australia needs to be in line with the United Nations Charter.”

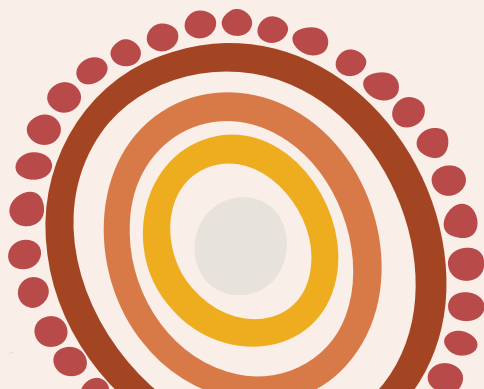
Overall, participant discussions reflected awareness that Aboriginal people have the right to control, access and benefit from the data about them. This right is core to the concept of Aboriginal Data Sovereignty.

Was there a consensus that researchers and organisations keep Aboriginal health data safe?

The consensus among participants is that researchers and health services need to be clearer and transparent about how they keep Aboriginal health data safe. This discussion occurred against the mistrust that participants and other community members have around the collection and use of the data. Mistrust stems from how researchers and governments of the past have used health research data to harm Aboriginal people.

“I think good research is good research. [...] That’s all really valuable. And some of these fellas get good, quality outcomes out of it. But historically, I think research is a dirty word.”

*“I totally agree with that. The minute you say research to any blackfella, they’re like, nah.”
[Collective laughter.]*



How researchers can protect Aboriginal health research data

Setting up locally specific recommendations for Aboriginal Data Sovereignty in Boorloo means getting details about specific questions. These questions include, where does our data sit and how do we decide who can access our data? The final question for participants therefore focused on their ideas for how researchers in Boorloo can achieve the principles of Aboriginal Data Sovereignty. The following questions guided discussion among the analysis team.

1. What suggestions did the participants provide for keeping health data safe in Boorloo?
2. Was there consensus or disagreement about where health research data from Aboriginal people in Boorloo should be kept?
3. What suggestions did the participants provide about deciding who can access Aboriginal health data collected in Boorloo?

Participants' suggestions about how to keep Aboriginal health research data safe in Boorloo

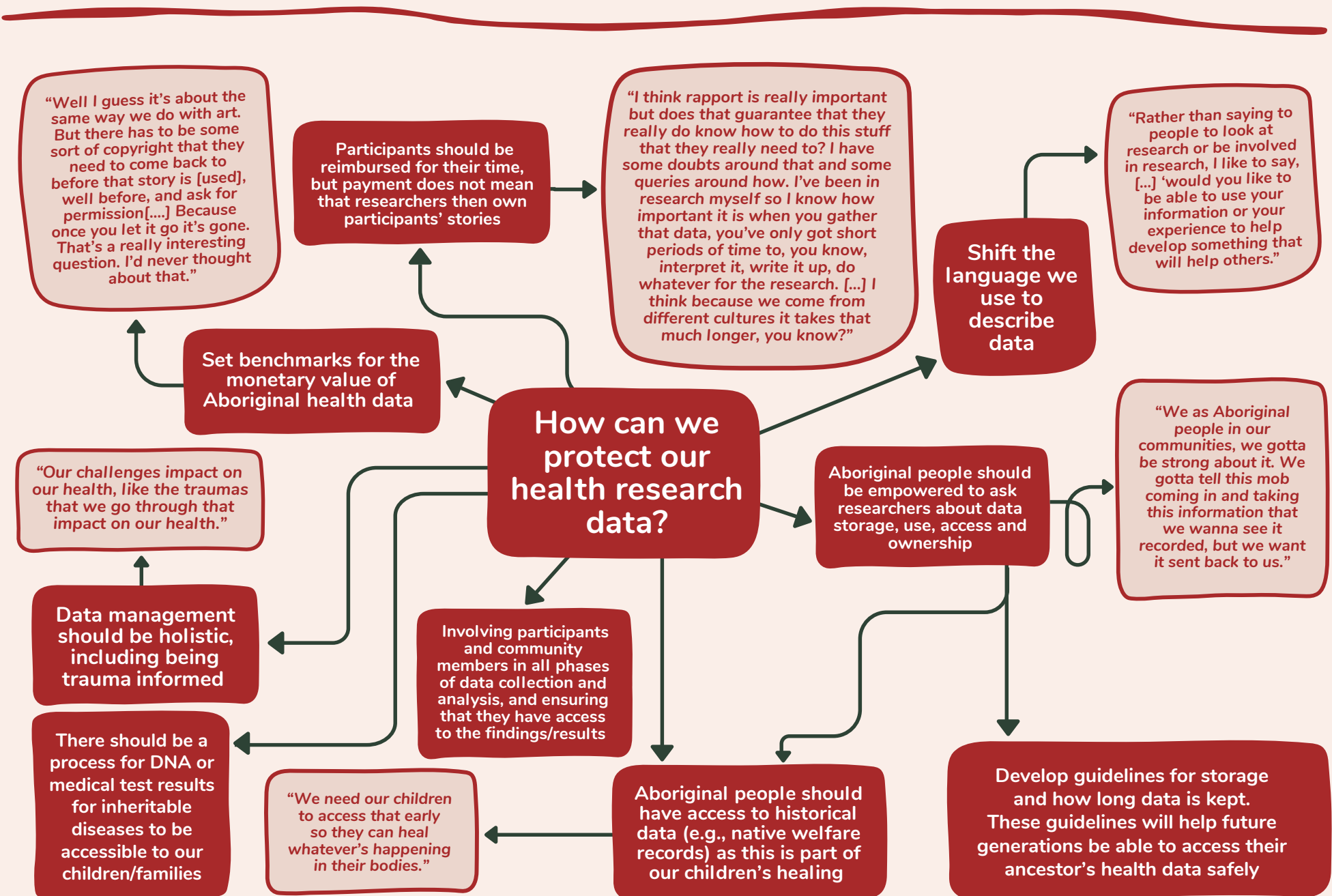
Participants suggested that using data safely means using it to make the changes that Aboriginal people want. Suggestions to achieve safe data usage include:

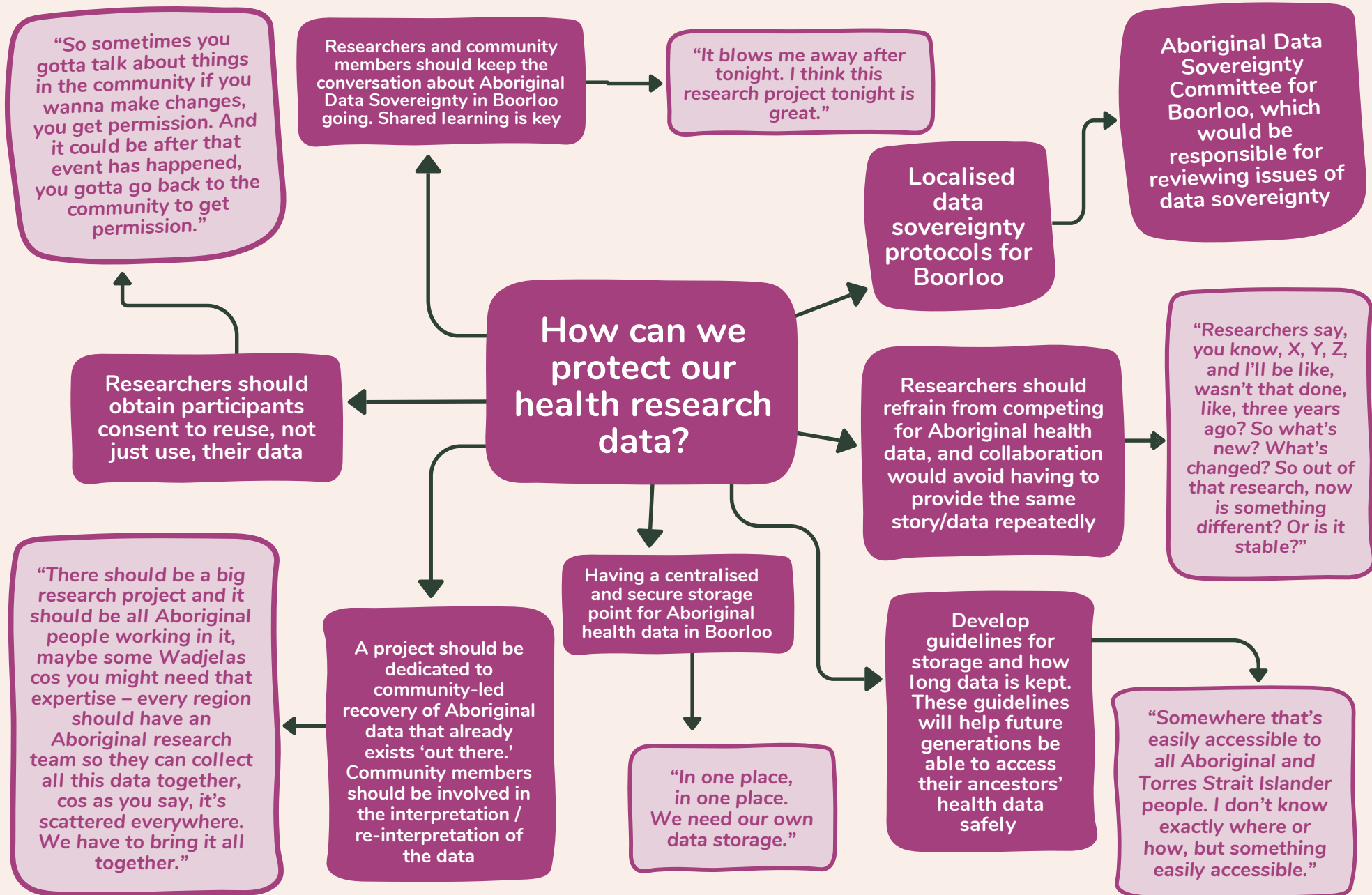
- Shifting the language we use to describe data, for example, saying 'sharing our stories' instead of research, or 'stories' instead of data. This should only be implemented if researchers commit to collecting data that tells a person's whole story (that is, contextualised data).

"Rather than saying to people to look at research or be involved in research, I like to say, [...] 'would you like to be able to use your information or your experience to help develop something that will help others?'"

- The inclusion of participants and community members in all phases of data collection and analysis, and ensuring that they have access to the findings.
- Having a centralised and secure storage point for Aboriginal health data in Boorloo.

"In one place, in one place. We need our own data storage."





- Researchers should refrain from competing for Aboriginal health data, as collaboration would avoid people having to provide the same story or data repeatedly.

“Researchers say, X, Y, Z, and I’ll be like, wasn’t that done, like, three years ago? So what’s new? What’s changed? So out of that research now is something different? Or is it stable?”

- Aboriginal people should be empowered to ask researchers about data storage, use, access and ownership.

“We as Aboriginal people in our communities, we gotta be strong about it. We gotta tell this mob coming in and taking this information that we wanna see it recorded, but we want it sent back to us.”

- Data management should be holistic, including being trauma informed.

“It’s more than health cos it’s a holistic approach. Cos our challenges impact on our health, like the traumas that we go through that impact on our health. I noticed the Health Department don’t go back to history, where the trauma starts cos that’s healing. If we know the first trauma that started with the individual, that’s where the healing will be. Work on that and work our way through. That’s the Aboriginal way of working. Flexible. And it’s not short term. It’s a long process for their healing, recovery, and treatment.”

- Researchers should obtain participants’ consent to reuse, not just use, their data.

“So sometimes you gotta talk about things in the community if you wanna make changes, you get permission. And it could be after that event has happened, you gotta go back to the community to get permission.”

- A project should be dedicated to community-led recovery of Aboriginal data that already exists ‘out there.’ Community members should be involved in the interpretation or re-interpretation of the data.

“There should be a big research project and it should be all Aboriginal people working in it, maybe some Wadjelas cos you might need that expertise – every region should have an Aboriginal research team so they can collect all this data together, cos as you say, it’s scattered everywhere. We have to bring it all together.”

- Participant financial reimbursement for providing data should only be in the context of the researchers having built relationships and established aftercare arrangements, to ensure a reciprocal relationship between researchers and participants. Otherwise, payment is seen as transactional. And there was recognition that this takes time and cannot be rushed.

“I think rapport is really important but does that guarantee that they really do know how to do this stuff that they really need to? I have some doubts around that and some queries around how. I’ve been in research myself so I know how important it is when you gather that data, you’ve only got short periods of time to, you know, interpret it, write it up, do whatever for the research. [...] I think because we come from different cultures it takes that much longer you know?”

- Participants should be reimbursed for their time, but payment does not mean that researchers then own participants' stories. Researchers should also have the understanding that participants have not 'sold' their data to researchers. Ownership of the data remains with the participants. As one participant noted in their definition of data sovereignty, those who collect the data believe they own it, but Aboriginal people are its custodians.

"It's stuff that we actually own ourselves. But everything Aboriginal, honestly, it's out there and everything that we have ever done."

- Set benchmarks for the monetary value of Aboriginal health data.

"Well I guess it's about the same way we do with art. But there has to be some sort of copyright that they need to come back to before that story is [used], well before, and ask for permission[...] Because once you let it go it's gone. That's a really interesting question. I'd never thought about that."

- There is an ongoing need to develop localised Aboriginal data sovereignty recommendations for Boorloo. One participant suggested an Aboriginal Data Sovereignty Committee for Boorloo, which would be responsible for reviewing issues of data sovereignty.

- Aboriginal people should have access to historical data (for example, native welfare records) as this is part of our children's healing.

"We need our children to access that early so they can heal whatever's happening in their bodies."

- There should be a process for DNA or medical test results for inheritable diseases to be accessible to our children/families.

"But I think it's important to have those stories – with us, with our medical records – if we ever want to close the gap. Those stories of how we come to have those chronic conditions are really important, and health data just doesn't have that at the moment."

- Develop guidelines for storage and how long data is kept. These guidelines will help future generations be able to access their ancestors' health data safely.

“Somewhere that’s easily accessible to all Aboriginal and Torres Strait Islander people. I don’t know exactly where or how, but something easily accessible.”

- Researchers and community members should keep the conversation about Aboriginal Data Sovereignty in Boorloo going. Shared learning is key.

“It blows me away after tonight. I think this research project tonight is great.”

Was there consensus about where researchers should keep Aboriginal health data in Boorloo? What suggestions did the participants provide about deciding who can access Aboriginal health data collected in Boorloo?

Overall, there was no consensus among participants on how Aboriginal Data Sovereignty principles could be upheld and on who should or should not have access to Aboriginal health data. This lack of consensus is likely due to the short period participants had to discuss the topic, which suggests a need for further discussion.

However, there was strong agreement among participants that issues of Aboriginal Data Sovereignty were of central importance. This includes generating data beneficial to Aboriginal people, collecting data that adds context and nuance to the numbers and having control over one’s own health research data.

Regarding storage specifically, participants agreed it was important that individuals be given options as to how and where their data is stored, for how long, and who should grant permission and have access to their data.

What do we want, and how do we achieve Aboriginal Data Sovereignty in Boorloo?

Following is a list of interim recommendations for researchers and health services collecting Aboriginal health research data in Boorloo.

We base these recommendations on information from our participants and the five Maiam nayri Wingara principles of Indigenous Data Sovereignty (Maiam nayri Wingara & Australian Indigenous Governance Institute, 2018). Ours are interim recommendations because we would need further discussions and planning to fully achieve Aboriginal Data Sovereignty for Aboriginal health research data in Boorloo.

Principle 1

MAIAM NAYRI WINGARA PRINCIPLE:

Exercise control of the data ecosystem, including creation, development, stewardship, analysis, dissemination and infrastructure.

For mob in Boorloo, this means Aboriginal people have the power to decide what happens to our knowledge, information and stories. We determine how they are created or developed, where and how they're kept, why they're being used, and who gets permission to use them.

Recommendations aligned with Principle 1

Recognise that Aboriginal people are the owners and custodians of the data they provide to researchers and health services.

Involve the Boorloo Aboriginal community in all phases of data collection that is about them, including study conceptualisation (that is, deciding on the study questions and methods), data collection, and the analysis and interpretation of health data.

Consult with Aboriginal community members in Boorloo to decide who can access the health data they collect. This decision can be through consultation specific to the project or service or broader consultation.

Make it clear to research participants when, how and for how long their data will be used and if it will be reused.

Plan ahead and get participants' informed consent for data sharing or reuse of data.

Conduct further consultation with Aboriginal community members on how their study protocols can reflect Aboriginal rights to their data.

Principle 2

MAIAM NAYRI WINGARA PRINCIPLE:

Data that are contextual and disaggregated (available and accessible at individual, community and First Nations levels).

For mob in Boorloo, this means that our knowledge, information and stories are told to show the full picture, and that this picture is available and accessible in a way that helps us understand what affects us directly, what works for us, why things might be the way they are. We can see the picture for each person, each community, and the whole country. The stories told reflect our diversity as Aboriginal people. Our stories make sense of the present by understanding the past.

Recommendations aligned with Principle 2

Consider if the health data you collect or have collected is sufficient to capture someone's story in context.

Make it clear to the Aboriginal community the journey their data takes, from the time it is collected to where and how it is stored and when it will be deleted (if at all).

Be intentional with the language being used and understand that Aboriginal and non-Aboriginal people have different perspectives on different words. Use clear language and take the language back down to the roots. Question the reason behind using jargon.

Consult Aboriginal community members in Boorloo about how local Aboriginal health data can be accessed for the benefit of the community. This includes access to data that has been broken down by detailed sub-categories (also known as disaggregated data).

Alongside Aboriginal community members, explore options for coordinating Aboriginal health research projects happening in Boorloo so that participants do not have to repeatedly share the same information with researchers.

Principle 3

MAIAM NAYRI WINGARA PRINCIPLE:

Data that are relevant and empower sustainable self-determination and effective self-governance.

For mob in Boorloo, this means that we collect the knowledge, information and stories that our communities need to make informed decisions in a lasting way. Stories are collected to empower Aboriginal people, not so that others can make decisions for us.

Recommendations aligned with Principle 3

Explore options with the Aboriginal community on how to develop Aboriginal Data Sovereignty protocols specific to Boorloo.

Alongside Aboriginal community members, develop guidelines for storage and how long Aboriginal health data is kept.

Alongside Aboriginal community members, explore the feasibility and role of an Aboriginal Data Sovereignty Committee for Boorloo.

Alongside Aboriginal community members, explore infrastructure options that allow Aboriginal health data from Boorloo to be held in one spot – a centralised and secure storage point (physically or digitally).

Principle 4

MAIAM NAYRI WINGARA PRINCIPLE:

Data structures that are accountable to Indigenous peoples and First Nations.

For mob in Boorloo, this means that the people who collect our knowledge, information and stories follow policies and processes that make sure they are led by Aboriginal people.

Recommendations aligned with Principle 4

Alongside Aboriginal community members, consider developing guidelines for a data collection process that appreciates relationship building, recognises the value of Aboriginal health data and does not take a transactional approach to receiving Aboriginal data (for example, options beyond receiving data for service or for minimal reimbursement).

Alongside Aboriginal community members, explore options for data infrastructure that allows for dynamic informed consent, which allows people to change their minds about what they have consented to. This could involve developing online platforms where participants can log into their own account to regularly review how their health data is being used and have an option of withdrawing their data at any point in time.

Spread awareness among researchers, participants and the Aboriginal community about the Indigenous Data Sovereignty requirements of WAAHEC (Western Australian Aboriginal Health Ethics Committee).

Keep the conversation about Aboriginal Data Sovereignty going among Aboriginal community members of Boorloo. These conversations would help build awareness and confidence among community members to assert their rights and ask questions.

Principle 5

MAIAM NAYRI WINGARA PRINCIPLE:

Data that are protective and respect our individual and collective interests.

For mob in Boorloo, this means that our knowledge, information and stories are collected, stored and used in a way that uplifts, respects and protects the needs of individuals and the community.

Recommendations aligned with Principle 5

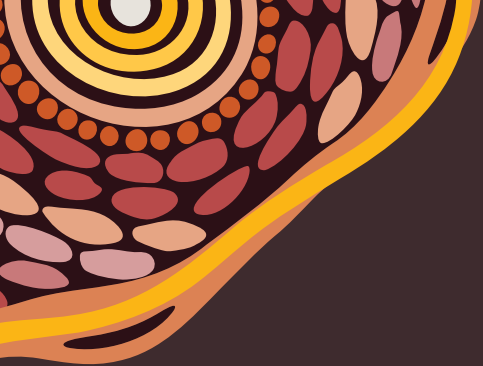
Clarify why you are asking to collect specific forms of data and have a process to check whether Aboriginal community members understand the purpose of collecting the data. Ideally, the reason for collecting Aboriginal health data in Boorloo should come from Aboriginal people of Boorloo.

Develop resources to empower community members to ask researchers and health services questions about use, data storage, access and the project's Aboriginal Data Sovereignty Plan.

Alongside the Aboriginal community, explore the feasibility of an Aboriginal project dedicated to the recovery of existing Aboriginal data.

Data management should be holistic, including being trauma informed. For example, have counselling available to people when they receive sensitive information.





Looking ahead

This community report is another step towards embedding Aboriginal Data Sovereignty within health research conducted in Boorloo. At the same time, we have ensured the document is also relevant to Boorloo-based health services because they, too, collect and manage what Aboriginal people consider health data.

In addition, some researchers use government and administrative data in their studies. Implementing the principles of Aboriginal Data Sovereignty will support Aboriginal people to have control over how their data is collected, used or reused, analysed and managed.

While health researchers have made inroads in implementing the principles of Aboriginal Data Sovereignty, there is still a long way to go. This project has focused on doing health research data the Aboriginal way, so that the data can help our community.

We hope health researchers will hear what the Aboriginal community in Boorloo have said and that our findings and recommendations will inform stronger adherence to the principles of Aboriginal Data Sovereignty. We also hope that health researchers will aim to conduct their studies with not just the kaat (head) but also the koort (heart).





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“This report is for the future of our kids. So we need to get it right to ensure they don’t go through what we are going through now.”

– PARTICIPANT FEEDBACK


Wungening
Aboriginal Corporation