Rainbow Knowledge: Broome & Kununurra Data Governance Statement

This statement outlines the governance protocol for data collected in the Rainbow Knowledge: Broome and Kununurra Project. The statement is guided by the "Good Data Practices for Indigenous Data Sovereignty and Governance" document developed by Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective (1).

1.Introduction

The Rainbow Knowledge: Broome and Kununurra project recognises the deep importance of data sovereignty for Aboriginal and Torres Strait Islander peoples in Australia. We are committed to employing principles of Indigenous Data Sovereignty (IDS) and acknowledge that IDS is necessary for Indigenous peoples' self-determination. We adopt the following definition of IDS:

> *"Indigenous Data Sovereignty' refers to the right of Indigenous people to exercise ownership over Indigenous Data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous Data."* (2)

In plain English, this means that decisions about what happens to the information provided by the Indigenous LGBTQA+ young people who take part in the Rainbow Knowledge: Broome and Kununurra project are made by the Indigenous LGBTQA+ community and are consistent with Indigenous ways of knowing, being and doing.

2. Data governance

Data governance is a crucial aspect of IDS. Data governance is defined as:

> *"Data governance is the power and authority over the design, ownership, access to and use of data."* (1)

In plain English, data governance means:

1. Which groups of people hold the data.

2. Which groups of people have the authority to access and use the data.

3. Which groups of people have the authority on how the data is used. Data is typically used in peer-reviewed publications, conference presentations and community reports to answer a specific research question.

2.1 What is the 'data'?

The Maiam nayri Wingara Indigneous Data Sovereignty Collective define Indigenous data as:

> *"In Australia, 'Indigenous Data' refers to information or knowledge, in any format or medium, which is about and may affect Indigenous peoples both collectively and individually."* (2)

In the Rainbow Knowledge: Broome and Kununurra project, the 'data' is all the answers that participants give to the interview questions. These include answers to yarning/interview prompts.

Data will be stored in an electronic file on investigators' password protected work computers.

2.2. How will the data be used?

The data will be used to answer research questions which align with the objectives of the Rainbow Knowledge: Broome and Kununurra project. These objectives are:

1. Qualitatively identify the SEWB, mental health, and service needs of Aboriginal LGBTQA+ young people in the Kimberly and how these may differ from youth living in urban centres.
2. Explore the impacts of living at the intersection of Aboriginal and LGBTQA+ identities on the SEWB and mental health of Aboriginal LGBTQA+ young people in the Kimberly, noting any regional differences across the Kimberley region.
3. Better understand the needs and preferences in relation to health service provision and support sought by Aboriginal LGBTQA+ youth in the Kimberley.
4. Feedback findings to local service providers and community members to enhance community knowledge of the needs of local Aboriginal LGBTQA+ youth.

Decisions around data use will be based on answering questions relevant to the Aboriginal and Torres Strait Islander LGBTQA + youth.

2.3. Who owns the data?

A commitment to IDS principles also means being open and clear about who owns the data given by participants. The data collected in the Rainbow Knowledge: Broome and Kununurra project is deidentified. We are able to re-identify data by linking a participant's alias to their name. Yarn-up groups and interviews will be audio-taped for the purpose of transcription and data analysis. Data analysis will involve members of the research team reading through transcripts to identify common themes in the experiences of participants. Audio files will be stored in a password protected file on the Telethon Kids Institute network and only accessible by team members.

A copy of the recordings (i.e. back up file) will be stored on a password protected USB drive which will be stored in a locked filing cabinet at the Telethon Kids Institute. All email transfer of data will use password projection on files. Only research team members will have access to the audio recordings to ensure participants' confidentiality. Participants will have the option of using an alias name in yarn-up groups/interviews and be addressed by this name, so that they are not identifiable on the audiotape. This is a common procedure in focus group/qualitative research designs to protect participant anonymity. A member of the research team will make a record of participants' names and chosen alias and keep this record as a password protected file.

This record is necessary for data analysis purposes; as part of the qualitative data analysis procedure, individual participants will be asked to review quotes and excerpts taken from the yarn-up groups/interviews that will be used in publications and agree that these quotes and excerpts are correct and have not been misinterpreted. Thus, the researchers will need to know which participant certain quotes came from. Participants will be able to request changes to, or the full removal of excerpts and quotes from publication manuscripts, and their researchers will fully comply with such request.

Participants in Rainbow Knowledge Broome and Kununurra will retain ownership of their data by being given a copy of their interview transcript.

3. Who will govern the data?

Transcripts of yarning groups/interviews will be held in an electronic file on project investigators' password protected work computers. The Project Advisory Group (PAG) guides project decisions regarding research questions, participant recruitment, data collection and analysis, and knowledge translation activities. Project Advisory Members are selected due to their lived experience as Aboriginal and Torres Strait Islander LGBTQA+ peoples who are living or have lived in the Kimberley and/or their experience supporting Aboriginal and Torres Strait Islander young people in the region.

3.1. Questions that the data governance mechanism will answer

- Requests from project investigators, community members, or academics external to the project (i.e., potential collaborators) to use the data to answer a research question outside the scope outlined in section 2.2.

- Requests from community members, or academics external to the project (i.e., potential collaborators) to access the data to answer a research question within the scope outlined in 2.2.

- Requests from community members for a project finding to be suppressed or have limited dissemination.

- Requests from community members for project data to be deleted.

4. Review Mechanism

This data governance protocol is implemented as of February 2024. It will be reviewed every five years by lead project investigator, Dr Bep Uink. Electronic copies of the data will be stored on a Telethon Kids Institute Microsoft Teams account, only accessible to project investigators, unless otherwise advised by the Project Advisory Group.

References

1) Lovett, R., Lee, V., Kukutai, T., Cormack, D., RAINIE, S. C., & Walker, J. (2019). Good data practices for Indigenous data sovereignty and governance. Good Data. Amsterdam: Institute of Network Cultures, 26-36.

2) https://www.maiamnayriwingara.org/key-principles