Walkern Katatdjin Data Governance Statement

This statement outlines the governance protocol for data collected in the Walkern Katatdjin (Rainbow Knowledge) National Survey. 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 Walkern Katatdjin 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)

That said, is not is not always possible, however, for Indigenous participants to retain ownership of their data, and ownership of Indigenous data can be transferred to researchers for the approved research purposes. This is the case with Walkern Katatdjin survey data.

In plain English, this means that decisions about what happens to the information provided by Indigenous LGBTQA+ young people who take the Walkern Katatdjin National Survey 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 Indigenous 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 Walkern Katatdjin National Survey, the 'data' is all the answers that participants give to survey questions. These include answers to questions on demographics (i.e., age, gender, postcode, sexuality, employment status, accommodation status, and disability status), social emotional wellbeing (connection to culture, connection to community, connection to Country, connection to family and kinship, connection to mind and emotions, connection to body, and connection to spirituality and ancestors), experiences due to being Indigenous and LGBTQA+, identity, family acceptance and rejection, psychological distress and suicidality, and experiences in health services.

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 Walkern Katatdjin. These objectives are:

- To quantitatively index the mental health (including suicidality) and social emotional wellbeing (SEWB) of Indigenous LGBTQA+ young people

- To determine the risk and protective factors for poor SEWB and mental health, and determine protective factors for Indigenous LGBTQA+ young people

- To understand Indigenous LGBTQA+ young peoples' experiences with health services and their service preferences

- To determine whether Indigenous LGBTQA+ young peoples' SEWB, mental health and experience in health services differ based on geographical location

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 Walkern Katatdjin national survey is anonymous. This means that we do not ask participants their name. This also means that we cannot link any participant to the data they provide. The reason for having an anonymous survey is so that participants can provide open and honest answers to survey questions without fear of these answers being linked back to them. This is particularly important for participants who are not 'out' about their gender and/or sexual identity.

IDS principles recognise that Indigenous peoples and communities should own the data they provide to researchers, but current Intellectual Property Law in Australia prevents communities from owning the data collected through the Walkern Katatjdin survey. Because Walkern Katatdjin survey responses are anonymous, participants cannot request that the answers they

provide be removed from the data file. Therefore, once a participant enters data into survey they are agreeing that their data will be held by the researchers.

3. Who will govern the data?

There are two phases to data governance in Walkern Katatdjin National Survey:

Phase 1: June 2020-Februrary 2021. Data will be held in an electronic file on project investigators' password protected work computers. Decisions on what research questions the data will be used to answer and who can access the de-identified data will be made in conjunction with project investigators and the Walkern Katatdjin Youth Advisory Group (YAG). The YAG consists of nine Indigenous LGBTQA+ young people from across Australia (i.e., members of the Indigenous LGBTQA+ community). YAG members are invited to give feedback and/or to coauthor all study publications. Investigators will follow best-practice guidelines for de-identifying data from the Office of the Australian Information Commissioner.

Phase 2: February 2021- onwards. Project funding ceases in February 2021. As of this date, we will no longer have funds to reimburse YAG members for their time and thus we do not expect them to play an ongoing role in data governance mechanisms. That said, we will invite YAG members to volunteer to continue their role in data governance. Should no YAG member volunteer, we will seek at-least two volunteers from the Indigenous LGBTQA+ youth community to uptake data governance. Data governance will additionally be shared with the Kulbardi Aboriginal Centre, Murdoch University. Kulbardi Aboriginal Centre exists to support Indigenous students at Murdoch University. It is well regarded within the local Noongar and Aboriginal and Torres Strait Islander community and is an avid supporter of social inclusion of Indigenous LGBTQA+ peoples. Thus, all data governance decisions will be made in conjunction with project investigators, the manager of Kulbardi Aboriginal Centre, and members of the Indigenous LGBTQA+ youth community. One of the Walkern Katatdjin project investigators is employed by the Kulbardi Aboriginal Centre

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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 August 2020. It will be reviewed every five years by project investigators, the manager of Kulbardi Aboriginal Centre and in consultation with Indigenous LGBTQA+ youth community members. The data will be stored for an unlimited amount of time unless otherwise decided by the data governance group.

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