‘Training Health Providers to work with Aboriginal and Torres Strait Islander LGBTQA+ Young People and their Families’

Research Data Management Plan

Purpose

This data management plan outlines how data from the research project entitled ‘Training Health Providers to work with Aboriginal and Torres Strait Islander LGBTQA+ Young People and their Families’ will be collected, stored, and governed during and after the completion of the project. This includes how decisions around if, and when, data will be made available for sharing. The plan enables researchers and partner organisations to conduct their research efficiently, authentically, and a way that is in accordance with CARE principles of Indigenous Data Sovereignty. The research data management plan is designed to support all aspects of the research data lifecycle, through creation and collection, storage, manipulation, sharing and collaboration, publishing, archiving and reuse.

1.1. Terminology

The following terms are used throughout this document:

ACCO. Aboriginal Community Controlled Organisations.

Data. Information collected by researchers, from research participants, to answer study questions.

Indigenous. Used to refer to Aboriginal and/or Torres Strait Islander peoples.

Findings. Results of the study generated by analysis of raw data.

LGBTQA+. Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Asexual, and other sexual and gender minorities.

NHRMC. National Health and Medical Research Council

Raw data. Data which has not been analysed.

1.2. The Research Project

The ‘Training Health Providers to work with Aboriginal and Torres Strait Islander LGBTQA+ Young People and their Families’ is a 3-year (2020-2023), 3-phase research project funded by the Australian Department of Health. The goals of each phase are as follows:

- **Phase 1:** to determine ACCOs’ training needs, both national and locally-specific, in relation to working with Indigneous LGBTQA+ youth and their families.
- **Phase 2:** to co-develop an inclusive training package with Indigenous LGBTQA+ youth, experts, and ACCO staff.
- **Phase 3:** to impelment and test the effiacy of the inclusive practice training programin increasing ACCO staff knowledge and confidence in working with Indigenous LGBTQA+ young people and their families.

1.2.1. The Research Participants

The project involves three (3) participant groups:

1. ACCO staff members
2. Aboriginal and Torres Strait Islander LGBTQA+ youth (14-25 years) co-design group
3. Subject matter experts

Each participant group is involved in co-design in Phase 2 of the project and therefore each participant group shares intellectual property, along with the researchers, of the training package that is developed.

At an organisational level, ACCOs are classed as partner organisations.

1.3. Pre-Data Collection Protocol

The partner organisations must agree upon the goals, objectives, and methods of the research. The research team will seek ethics approval for the study from appropriate NHRMC ethics boards. Participants will provide informed consent prior to participating in any data collection.

1.4. Data Collection Protocol

Phase 1. Data collected in Phase 1 will be qualitative data about the training needs of ACCO staff in regards to inclusive practice with Aboriginal and Torres Strait Islander LGBTQA+ youth and their families. Additional qualitative data will come from subject matter experts and relate to expert opinion on the training needs of ACCOs. Data from ACCO staff will be collected via focus groups and one-on-one interviews. Data from subject matter experts will be collected via one-on-one interviews. All data provided will be kept confidential.

Phase 2. Data collected in Phase 2 will be components of an inclusive care training package for working with Aboriginal and Torres Strait Islander LGBTQA+ youth and their families. Specific content of this training will be informed by Phase 1, however, will likely touch on helping ACCO staff understand LGBTQA+ specific terminology, specific health risks associated with being Indigenous, young and LGBTQA+, how to talk with Indigenous LGBTQA+ young people and their families about sexuality and gender diversity, and culturally-specific considerations when working with Indigenous LGBTQA+ young people (e.g., how to manage gendered 'men's' and 'women's' business). Data will be provided by all three participant groups listed in section 1.1.2. Data from all participant groups will be collected via co-design workshop groups and one-on-one interviews. All data will be kept confidential.

Phase 3. Data collected in Phase 3 will be quantitative and qualitative data on the efficacy of the inclusive practices training package. Data will be collected from ACCO staff who undergo the training and via pre- and post-training online surveys. All data provided will be kept confidential.

1.5. Post-Data Collection Protocol

Phase 1 and 2 data will be audio recorded and transcribed for the purpose of this research. These audio files and transcripts constitute the 'raw data'. Audio files will be stored at the lead research institution (Telethon Kids Institute). Transcripts will be made available to participants for the purpose of checking accuracy of what has been transcribed and to provide them the opportunity to remove any comments in the transcript. Transcripts will be stored electronically at the lead research institution (Telethon Kids Institute). Section 'X' outlines mechanisms for sharing and accessing this data.

Raw data will be converted into study findings via data analysis. During data analysis, the researchers will look for common themes across the transcripts to identify key training needs of ACCOs (Phase 1) and core components to include in an inclusive practice training package (Phase 2).

1. What are ACCO staff/experts' definitions and perceptions of 'inclusive practice'?
2. What are the current practices of ACCO staff/experts when working with LGBTQA+ youth and their families?
3. What additional training needs do ACCO staff have when working LGBTQA+ youth and their families?
4. What are the core competencies needs to work effectively with Indigenous LGBTQA+ youth and their families?
5. At what level of the organisation should training be targetted? (e.g., individual staff, organisational, human resources, clinical staff)?
6. What format should a training package take? (e.g., online, in-person, length of training)?

Answers to the above questions constititue the 'findings' of Phase 1. Note: The researchers and the partner organisations agree to maintain confidentiality of all data provided by individuals interviewed and only identify persons in written material who give their approval to do so.

In Phase 2 analysis, researchers will assess transcripts for the purpose of writing an inclusive practice training package for Indigenous LGBTQA+ youth and their families. The training package therefore constitutes the ‘findings’ of Phase 2.

Phase 3 data will be stored in a digital data file using the Statistical Package for the Social Sciences (SPSS). The data file will be stored at the host institution (Telethon Kids Institute). Participants’ responses to survey questions constitute the ‘raw’ data for Phase 3. Phase 3 raw data will be transformed into findings via the researchers applying statistical analysis.

The data set may be drawn on by the researchers, partner organisations, or other community groups beyond the life of this project. Matters of data sharing will be handled by the Data Governance Committee (see section 2). Participant will provide written consent to allow re-use of this data for future research prior to participating in the study.

2. Data Governance

“Indigenous Data Governance refers to the right of Indigenous peoples to autonomously decide what, how and why Indigenous Data are collected, accessed and used. It ensures that data on or about Indigenous peoples reflects our priorities, values, cultures, worldviews and diversity” (https://www.maiamnayriwingara.org/key-principles).

This project has been developed in consultation with ACCOs across Australia. The project is lead by an Indigenous lead CI and two of the three Indigenous researchers are also LGBTQA+.

A data governance committee (DGC) will be established for this project. The researchers will also ask each partner organisations to nominate a member of their organisation to serve as a member of the DGC, as well as ask the Indigenous LGBTQA+ youth co-design group to nominate a member to serve on the DGC. The DCG will be established prior to beginning data collection. Membership on the DGC will last for the duration of the project plus 12 months post project ending, at which point, membership will be reviewed and amended if necessary.

The DGC’s primary roles is to decide on when, how, and to whom data collected at each Phase of the project is made available to community members, and other researchers, as well as to decide if and when any of the raw data collected in the project is deleted or suppressed. In helping inform their decision making, the DCG will pull from the protocol developed by the Mayi Kuwayu National Study of Aboriginal and Torres Strait Islander Wellbeing team (https://mkstudy.com.au/wp-content/uploads/2020/07/Data-Application-form.pdf), whom are industry leaders in application of the principles of Indigenous data sovereignty. Consistent with this protocol, raw data from the project will **never** be shared with non-project team members. Instead, interested parties can request for specific analyses which will be run by the researchers. If community members or other researchers wish to apply for access to some or all the data collected in the project, they will be asked to provide written responses to the following questions:

i. What is the nature and purpose of the project proposed?
ii. What is the research question(s) that will be answered with this project data?
iii. Who is leading the proposed project? (i.e., ACCO or other community organisation, student researcher, academic researcher, government organisation?).
iv. How will the proposed project meet the principles of Indigenous Data Sovereignty laid out by the Maiam nayri Wingara original and Torres Strait Islander Data Sovereignty Collective (https://www.maiamnayriwingara.org/about-us)
v. Proposed time frame for project completion
vi. Data analysis plan
vii. Findings dissemination plan

The DGC does not dictate where or how *findings* of the project will be made available, although their advice will be respectfully sought on the most effective ways to disseminate project findings.

3. Dissemination of Findings

As this research is commissioned by the Australian Department of Health for the purpose of increasing the capacity of ACCO staff to work with Indigenous LGBTQA+ young people and their families, the primary method for dissemination of findings will be through a series of project reports which outline findings from each phase of this study (a total of 4 reports). The funder has requested an evaluation component to this research therefore there will be a report prepared at the conclusion at each phase will initial findings and a final project report completed at the conclusion of the project. Thus, project findings will be disseminated in the following publications, which will be made publicly available:

i. Needs Assessment Report (completed at the end of Phase 1)
ii. Training Development Report, including details of the inclusive practice training package (completed at the end of Phase 2)
iii. Implementation and Efficacy Report (completed at the end of Phase 3)
iv. Final Project Evaluation Report (completed at conclusion of the project).

We additionally anticipate that findings will be disseminated via conference presentations and publication in peer-reviewed journal articles. Non-researcher members of the DGC will review and provide input on all publications prior to their submission to the funder and to peer review.

3.1. Authorship

Partner organisations will be invited to co-author all publications arising from this project. Consistent with the Vancouver Protocol (https://research.ntu.edu.sg/rieo/Documents/Foundational%20Documents/Vancouver%20Protocol.pdf) authorship requires organisations and individuals to have made a significant intellectual contribution to the publication. Because ACCOs, subject matter experts, and the Indigenous LGBTQA+ youth co-design group are co-designing the training package, they are automatically included as authors on any publication which presents this training package (unless they request otherwise).

4. Oversight

The lead CI will be responsible for the routine supervision of the datasets created in this project, including anonymizing, storage, and archiving of datasets. The lead CI will provide statements indicating how this data management plan has been adhered to (or any deviations from the plan) via regular reports to ethics bodies which have provide approval for the project.

Should any of the researchers, partner organisations, members of the DGC, and/or participants develop concerns regarding the application of this data management plan they can report these concerns verbally or in writing to the lead CI. If they do not feel comfortable reporting these concerns to the lead CI, they can report concerns to the ethics board(s) which provided approval for the project. All researchers, partner organisations, members of the DGC, and participants will be provided contact details of relevant ethics committees.