

## Pride Yarns Aboriginal and Torres Strait Islander Peoples' Data Sovereignty Statement

This statement outlines the Aboriginal and Torres Strait Islander Peoples' Data Sovereignty protocol for data collected through the Pride Yarns study. The data collected in the study includes data collected through co-design workshops, participants interviews, pre and post surveys and evaluations (data collection activities). The statement is guided by the "Good Data Practices for Indigenous Data Sovereignty and Governance" document developed by Maïam nayri Wingara Indigenous Data Sovereignty Collective (1). The IDS Readiness Assessment Guide developed by The Lowitja Institute also informs our approaches to Aboriginal and Torres Strait Islander Peoples' Data Sovereignty (3). This is to ensure that we give careful consideration about how the data is collected, stored, and used. Furthermore, that we are upholding Aboriginal and Torres Strait Islander peoples' rights and self-determination through ensuring that the data we collect is relevant, represents the intent of Aboriginal and Torres Strait Islander peoples while preserving the confidentiality and cultural safety of co-designers and participants.

This document should be read in conjunction with the Indigenous Cultural Intellectual Property Protocol.

### 1. Introduction

The Pride Yarns project has three (3) phases:

**Phase 1:** The objective of Phase 1 is to co-design a program model (entitled *Pride Yarns*) and guide for an Elder-led, intergenerational support program to enhance the social and emotional wellbeing (SEWB) of Aboriginal and Torres Strait Islander LGBTQA+ young people (14-25 years).

**Phase 2:** The objective of Phase 2 is to determine i) whether the *Pride Yarns* program model is acceptable, ii) who uses the program, and iii) whether there are changes in youth participants' feelings of acceptance, belief that they can be both Aboriginal and LGBTQA+, and SEWB.

**Phase 3:** The objective of Phase 3 is to develop an evidence-based toolkit (the 'Toolkit') that can be used by health services who work with Aboriginal and Torres Strait Islander young people, including ACCOs, LGBTQA+ services and other non-Aboriginal organisations.

The Pride Yarns project recognises the deep importance of data sovereignty for Aboriginal and Torres Strait Islander peoples in Australia. We are committed to employing principles of Aboriginal and Torres Strait Islander Peoples' Data Sovereignty and acknowledge that it is necessary for Aboriginal and Torres Strait Islander peoples' self-determination. We adopt the following definition of Aboriginal and Torres Strait Islander Peoples' Data Sovereignty:

*'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)

Ownership means that the people whose data is collected have control over what data is collected about them, how it is collected, where and how it is stored, how it is analysed and interpreted, who can access the data, how long the data is kept and decisions around deletion of the data. The Review of the National Agreement on Closing the Gap Report received numerous submissions for the Agreement to be amended in support of Aboriginal and Torres Strait Islander Peoples’ Data Sovereignty (4).

Pride Yarns also recognises the rights Aboriginal and Torres Strait Islander people have in the protection of their traditional arts and culture ‘Indigenous Cultural and Intellectual Property’ (ICIP). The key principle of ICIP is that of self-determination (5).

The people whose data is being collected in the Pride Yarns project are:

Aboriginal and Torres Strait Islander LGBTQA+ young people (14-25 years) living in Perth.
ACCOs with a health and wellbeing focus.
Local Elders and community leaders in Perth, WA.
Perth-based LGBTQA+ service providers.
Aboriginal and Torres Strait Islander community members in Perth, WA.

## 2. Data governance

*Data governance* is a crucial aspect of Aboriginal and Torres Strait Islander Peoples’ Data Sovereignty. 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. In addition to these the Pride Yarns Findings will be used to develop an Elder-led Program Model, Toolkit and Guide that responds sensitively to the needs of Aboriginal LGBTQA+ young people.

### 2.1 What is ‘Indigenous Data’?

In this statement:

**Indigenous Data** has the same meaning as Indigenous data in the Maiam nayri Wingara (pronounced mai-am nai-ree win-ga-ra) Indigenous Data Sovereignty Collective:

*“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) (Indigenous Data)*

In Pride Yarns Indigenous Data is all the information research participants provide in discussions and activities during the data collection activities (co-design workshops, participant interviews, pre-and post-surveys) and also includes:

- Yarning group transcripts
- Participant survey responses
- Participant feedback
- Project methodology
- Governance group meeting minutes.

**Data non-Indigenous-related:** Data non-Indigenous-related is any information and materials including, methods, reports or instructions, and does not include Indigenous Data, that may be provided by the research participants to the Research team or research team members in connection to the Pride Yarns project.

**Findings:** Findings are reports, publications, and program evaluations and are owned by the institutions involved in the Pride Yarns project and the by the funding body.

Specific to the Pride Yarns project **Findings** are:

1. The Pride Yarns program model that will be developed from this project and associated program guide and toolkit.

## 2.2. Data Storage

Indigenous Data and Data non-Indigenous-related will be stored a password protected computer at the Kurongkurl Katitjin Centre at Edith Cowan University and on SharePoint site hosted by Edith Cowan University which the manager of the Kurongkurl Katitjin will be able to access. Electronic backups of the data will be stored on investigators' password-protected computers at their respective institutions (Kids Research Institute Australia, University of Western Australia, Murdoch University, Wungening Aboriginal Corporation, Yorgum Healing Services, Youth Pride Network).

Paper copies of Data (e.g., interview transcripts and notes) will be stored in a locked file in the office of a research team member at Edith Cowan University.

Indigenous Data and Data will be stored for an unlimited amount of time unless otherwise decided by the data governance groups. After the completion of the project, the data and Indigenous Data will be stored at a central location such as Kurongkurl Katitjin (if this is what is decided by the Aboriginal Governance Groups). A contact email will be provided so that there will be an ongoing point of contact after the completion of this research project.

## 2.3. How will the Indigenous Data be used?

The Indigenous Data will be used to answer research questions which align with the objectives of the Pride Yarns Project. These research questions are:

- What does a co-designed, Elder-led intergenerational support program for Aboriginal and Torres Strait Islander LGBTQA+ young people look like?
- How can an Elder-led intergenerational support program facilitate safe and supportive conversations about the intersection of culture, sexuality, and gender diversity between Aboriginal and Torres Strait Islander LGBTQA+ young people and their Elders?
- To determine the acceptability of an Elder-based LGBTQA+ program amongst Elders, young people, and service providers.
- To undertake an evaluation to determine the demand for the program.
- The determination of the immediate impact of the program in terms of pre-post program changes in Aboriginal and Torres Strait Islander LGBTQA+ young

peoples' feelings of acceptance within the Aboriginal community, beliefs that Aboriginal and LGBTQA+ identities can coexist, and overall social and emotional wellbeing.

- To develop an evidenced-based toolkit and guide for Elder-led, intergenerational support programs to improve the social and emotional wellbeing of Aboriginal and Torres Strait Islander LGBTQA+ young people across Australia.

#### **2.4. Who owns the Indigenous Data, Data non-Indigenous-related and Findings?**

A commitment to Aboriginal and Torres Strait Islander Peoples' Data Sovereignty principles as laid out by the Miam Nayri Wingara Collective (2), also means being open and clear about who owns the Indigenous Data and Data non-Indigenous-related given by participants. The Indigenous Data and Data non-Indigenous-related collected in the Pride Yarns co-design groups, participants interviews, and pre and post surveys will be used in ways that ensure it correctly reflects the intent of participants.

Each participant will be given a copy of the Indigenous Data and Data non-Indigenous-related they provide to the project and will retain ownership of their Indigenous Data and Data non-Indigenous-related. Once participants sign study consent forms, they will be consenting to the research team holding the Indigenous Data and Data non-Indigenous-related and becoming custodians of the Indigenous Data and Data non-Indigenous-related. A participant's Indigenous Data and Data non-Indigenous-related from co-design sessions cannot be deleted from recordings or transcripts as it will be re-identifiable.

#### **2.5. Intellectual Property.**

Intellectual property in the Pride Yarns program model and Findings will be owned as agreed between the research team, partners (Wungening Aboriginal Corporation, Yorgum Healing Services, Youth Pride Network), the Youth Governance Group and the Aboriginal Governance Group and their contractual obligations between the parties. All parties who contribute to the development of the Pride Yarns program model and subsequent program guide and toolkit will be acknowledged as authors of the program, where possible.

The Pride Yarns intervention may be used for commercial benefit of the parties and the Australian community, and any other obligations ECU is required to meet under its agreement with the funder, the Commonwealth of Australia for this project.

#### **2.6. Indigenous Cultural and Intellectual Property**

Indigenous Cultural and Intellectual Property (ICIP) refers to "Indigenous peoples' rights to their heritage. Heritage consists of the intangible and tangible aspects of the whole body of cultural practices, resources and knowledge systems developed, nurtured and refined by Indigenous people and passed on by them as part of expressing their cultural identity. The heritage of an Indigenous people is a living one and includes items that may be created in the future, based on that heritage" (6).

The Pride Yarns program does not seek to record and utilise traditional knowledges such as stories, dances, music, artforms, oral histories, medicines, etc. Nonetheless, we recognise that the Pride Yarns program may incorporate Intangible Cultural Heritage, such as Indigenous ways of doing and being, (e.g., yarning, relationality).

All participants will be offered the opportunity to be named as authors of the Pride Yarns program if they so choose, noting the potential need for confidentiality among

some participants. Governance and participants are made aware that the Pride Yarns program will be made available to organisations, including Aboriginal Community Controlled Organisations, and the general public, through reports, open access repository such as the Australian Consortium for Social and Political Research Inc. (achievements or databases listed under the National Centre for Biotechnology Information) and in consistent with the National Health and Medical Research Council's policy about dissemination of research findings, journal articles and conference seminars or presentations. Knowledge included in the program may be ineligible for future patents. The Governance Groups assist the research team with determining which cultural knowledge is inappropriate to include in final program (e.g., locally-specific cultural knowledge, sensitive material, sacred material, men's/women's business).

The Aboriginal Governance Groups will make the decisions (through consensus) about how ICIP is collected and shared (including on-line). The Aboriginal Governance Groups will make the decisions (through consensus) as to how the ICIP generated will be used in publications, toolkits, guides or other educational materials.

### **3. Who will govern the data?**

The Pride Yarns Aboriginal Governance Group and the Pride Yarns Youth Governance Group (consisting of Aboriginal and Torres Strait Islander LGBTQA+ young people) will govern all data collected through the Pride Yarns project. They will make the decisions about how Indigenous Data is collected, where it is stored, how it is analysed and who may have access. The Governance Groups will provide advice and make the decisions about the cultural knowledge associated with the project.

#### **3.1. Questions that the data governance mechanism will answer.**

- Who will own the Indigenous Cultural Intellectual Property for the project.
- Review and approval of research questions, data collection methods, data analytic methods, interpretation of results, and dissemination and knowledge translation methods.
- Determining the processes for approval of data use, such as by consensus. In situations where part, or all of research work is not approved the reasonable steps the research team can take to address concerns.
- Requests from project investigators, community members, or academics who want to use the data for questions outside the scope of Pride Yarns.
- 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 the objectives of Pride Yarns.
- Requests from community members for a project finding to be suppressed or have limited dissemination.
- What will happen to data resulting from participants who may be deceased during or post the project.
- Requests from community members for Findings to be deleted.

### **4. Review Mechanism**

This data governance protocol is implemented as of March 2024 and is active up until the end of the Pride Yarns project. Decisions on the data governance mechanism post-conclusion of the study will be made in conjunction with the research team members, the Aboriginal Governance Group and the Youth Governance 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>
3. Griffiths K.E., Johnston M., Bowman-Derrick S. 2021, Indigenous Data Sovereignty: Readiness Assessment and Evaluation Toolkit, Lowitja Institute, Melbourne.
4. Commonwealth of Australia (2024). Review of the National Agreement on Closing the Gap, Canberra.
5. Australian Government Information Sheet ICIP. <https://www.artslaw.com.au/information-sheet/indigenous-cultural-intellectual-property-icip-aitb/>
6. Janke, T. (2005). "Managing Indigenous Knowledge and Indigenous Cultural and Intellectual Property." Australian academic and research libraries 36(2): 95-107.

## Further resources:

- British Columbia First Nations' Data Governance Initiative (BCFNDGI): A Collaboration of Nations Asserting Data Sovereignty (website)
- United Nations Declaration on the Rights of Indigenous Peoples (declaration)
- The CARE Principles for Indigenous Data Governance (paper)
- Maim nayri Wingara (website)
- Global Indigenous Data Alliance (website)
- Indigenous Data Sovereignty and Policy (paper)
- Indigenous Data Sovereignty: Toward an Agenda (book)
- Kowa Tools and Resources (website)
- OCCAAARS Framework: A framework for operationalising Aboriginal and Torres Strait Islander data sovereignty in Australia: Results of a systematic literature review of published studies (paper)
- Good data practices for Indigenous data sovereignty and governance (book chapter)