

Acknowledgment of Country

Thank you to the Wadjuk Noongar peoples whose land we are learning and gathering on today. I pay my respects to Elders past and present.

Thank you to Aboriginal and Torres Strait Islander LGBTQA+ community members and Elders.



@skyangelwings

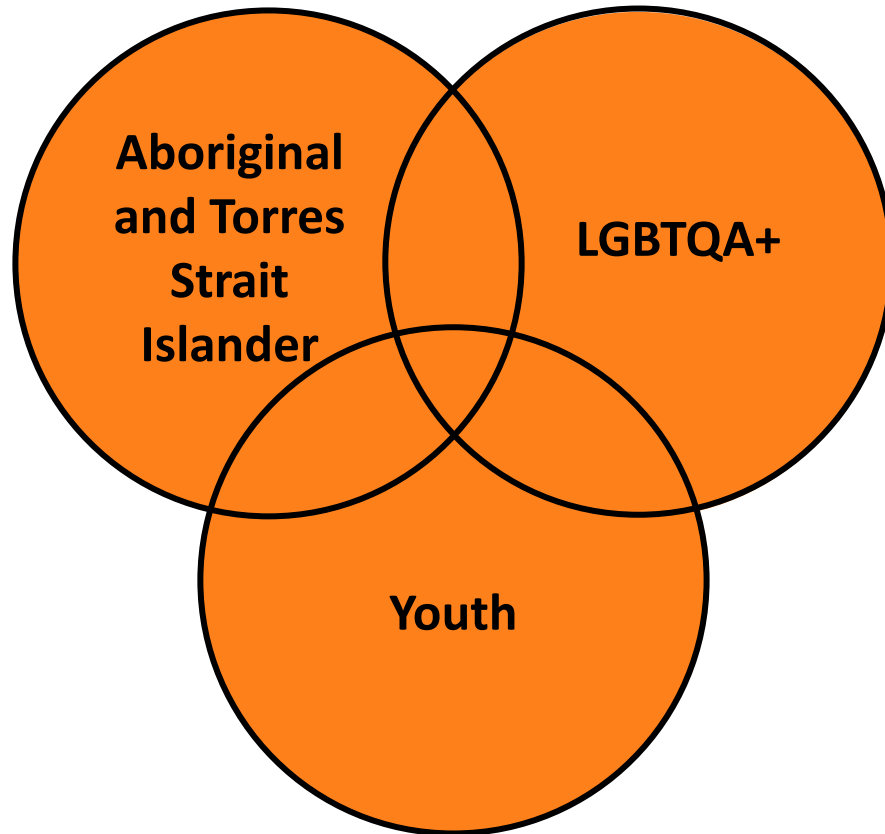
IDS Case study- Walkern Katatdjin National survey



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Walkern Katatdjin
Rainbow Knowledge



Phase 1: Yarning groups and interviews

Phase 2: National survey

Phase 3: Co-design

Case study- Walkern Katatdjin National survey

What is Indigenous Data for Walkern Katatjdin?

Interviews and Yarning groups

All interviews and yarning group transcripts

National Survey

All the answers that participants give to survey questions

- Demographics (i.e., age, gender, postcode, sexuality)
- Social and emotional wellbeing
- Experiences due to being Indigenous and LGBTQA+
- Psychological distress and suicidality
- Experiences in health services

Case study- Walkern Katatdjín National survey

Who owns the data we are going to collect?

Who is the Aboriginal and Torres Strait Islander LGBTQA+ youth community?

Things to consider:

- Pragmatics
- Who talks for who?
- LGBTQA+ bias



Decision for data to be governed by interested representatives from Aboriginal and Torres Strait Islander LGBTQA+ communities.

Maiam nayri Wingara Principles

1. Indigenous people should exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.

- Creation – invitation from Aboriginal and Torres Strait Islander LGBTQA+ community for the research
- The project is lead by an Aboriginal researcher and 2 of the 5 investigators are Aboriginal LGBTQA+
- Consultation of Youth Advisory Group (YAG) and Indigenous Governance Group (IGG) on study research questions
 - E.g., addition of strengths-based research question

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.

Maiam nayri Wingara Principles cont'd

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

- For survey data...
 - Pre-registration of 3 core studies
 - RQ's, hypotheses (confirmatory or exploratory), analytic techniques reviewed by YAG and IGG - YAG members co-authors of the OSF documents
 - YAG co-authorship (not just review) of papers
 - Fortnightly writing sessions – what is the story we want to tell? How can we contextualise and understand study findings?
- Uink et al.*, (under review). Health Promoting Factors for Aboriginal and Torres Strait Islander LGBTQA+ young people. *Child Development*.

Maiam nayri Wingara Principles cont'd

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

DATA GOVERNANCE MECHANISM

1) Which groups of people hold the data?

Once a participant enters data into the survey they are agreeing that their data will be held by the researchers.

Digital data is held on TKI SharePoint

Access to SharePoint given to research team members & Manager of Kulunga (Aboriginal Unit at TKI)

Maiam nayri Wingara Principles cont'd

DATA GOVERNANCE MECHANISM

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

ACCESS: Research team, Manager of Kulunga

USE: Research team, permission given by YAG and IGG.

Current request from Research Team to YAG & IGG:

- to answer questions in the way laid out in survey pre-registration document
- permission to publish in certain outlets

Note:

As per our IDS statement, data can currently only be used to:

- quantitatively index the mental health (including suicidality) and social emotional wellbeing (SEWB) of Indigenous LGBTQA+ young people
- determine the risk and protective factors for poor SEWB and mental health
- understand Indigenous LGBTQA+ young peoples' experiences with health services and their service preferences
- determine whether Indigenous LGBTQA+ young peoples' SEWB, mental health and experience in health services differ based on geographical location

Maiam nayri Wingara Principles Cont'd

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

- The desire to answer questions about Aboriginal & Torres Strait Islander LGBTQA+ young peoples' SEWB and mental health **in itself represents** a move towards data disaggregation.
- Able to disaggregate by state/territory- uncover more localised trends –i.e., group is not homogenous
- Findings can be customised to local(ish) contexts
- Community forums and reports for data analysis and dissemination of findings

Maiam nayri Wingara Principles Cont'd

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



The Aboriginal and Torres Strait Islander Suicide Prevention Evaluation Project (ATSISPEP)

Young Aboriginal LGBTI people are killing themselves. We need to protect them
Allan Clarke for IndigenousX

Realising I'm gay was almost too much to bear through my teenage years, writes NITV journalist and **IndigenousX** host **Allan Clarke**. We need to stand up to homophobia



Sexuality and Gender Diverse Populations (Lesbian, Gay, Bisexual, Transsexual, Queer and Intersex - LGBTQI)
Roundtable Report

Friday 20th March 2015
The Healing Foundation, Canberra

Maiam nayri Wingara Principles Cont'd

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

- Who makes decisions on data use, suppression etc.?

While project is funded:

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).

Partnership agreements with ACCOs: review publications for use of data

Kulunga overseeing TKI team activities.

Maiam nayri Wingara Principles Cont'd

5. Data that is protective and respects our individual and collective interests.

TENSION – what is the *collective interest* here?

- Consideration that LGBTQA+ voices are often left out of Aboriginal community conversations
- Ensuring individual (participant) voices heard as well as wider community (e.g., through Elders forums)

Overcoming Institutional Barriers to IDS

- 1) Funder & university/institute considerations – standard grant agreement will state the IP sits with the host institution
 - Contracts/legal process automatically excluded notions of IDS
 - University legal teams not yet equipped for IDS discussions

Workarounds:

- Discussion with contracts team to include clause to respects IDS principles
- Memorandum of Understandings (MOU) between community organisation and host institute
- Strong data governance mechanisms
- Community organisations becoming host institutions in research
- Community-based infrastructure for storing and governing data?

Overcoming Institutional Barriers to IDS

2) Grant/project funding is time limited

- In WK, YAG members and IGG members are paid...who will be responsible for data governance once the project funding expires?

Post-funding data governance:

- 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.

Acknowledgements

- Participants
- Project partners



Shakyrrah Beck

she/her

Shakyrrah is currently studying year 12 while doing art commissions on the side as both a way to stay calm and support her family. Shakyrrah is 19 years old and has 2 children under the age of 2. She is a Narungga woman but was welcomed in by the Kaurna people from when she was young and has grown up with them.



Skye Milton

she/they

Skye is 17 and recently graduated year 12. She is a strong believer of equality and does their best to show this in their art. They are Aboriginal and wish to learn more about their culture from their mum and the people in her life. She does commissions in hopes to become a full time artist and possibly go to uni to study art and character design.

