

Taking the lead: First Nations peoples leading sexual health research in the Northern Territory





Decolonising methodologies

Prioritising Aboriginal people's:

- active role in research leadership
- expert knowledge about themselves, their circumstances and health solutions
- socio-culturally situated knowledges and understandings of the world as basis for health actions and solutions

Beyond ethical research practice:

- > social justice
- self-determination and community control

Unacceptable persistent sexual health disparities between Aboriginal and non-Indigenous young people

Little evidence of working with Aboriginal young people as experts on their own lives and researchers to resolve (locally-identified) challenges they face

Documenting young people's role as co-researchers





The MOST trial

The 'More Options for STI Testing' (MOST) trial in Northern Territory, ending 2020, evaluates an incentives strategy to increase clinic-based STI testing among young Aboriginal people





Prior to the start of the trial, young Aboriginal people in one remote setting were employed as co-researchers:

- trained to conduct qualitative research to better understand young people's experiences accessing STI testing services
- participated in workshops to co-design the trial strategies used









Capabilities and expertise...

...of young Aboriginal people as researchers:

- Completion of training and responsibilities with enthusiasm, interest and growing self-esteem
- Average length of interviews between peer researchers and peers (38 minutes) compared with that of the study investigators with the peer researchers (38 minutes)
- Deep data set on young people's lived experiences:
 - socio-ecological factors influencing engagement in clinic-based STI testing
 - sexual health risk and risk reduction practices
 - perceptions of existing sexual health education
 - vulnerable contexts that enhance risk of STIs (and pregnancy)
 - peer-peer sexual health communication and negotiation





'Peer researchers' are members of a community, who through research training, become trusted members of a research team and work as researchers within their own communities, taking responsibility for leading research processes

Participatory training

Interviews with peer researchers

Peer-led interviews & debriefing





Participatory training

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Peer-led interviews & debriefing

- 4 day participatory training course with focus on:
 - semi-structured in-depth interviewing skills
 - applied research ethics
 - identification of interviewees
 - data management
 - practice, practice, practice...





Participatory training

Interviews with peer researchers

Peer-led interviews & debriefing

- In-depth interviews conducted with all 8 youth researchers during training
 - enabled preparation of draft topic guides
 - 'teaching' opportunity experience of interviewing drawn on during training
 - capability building for two Aboriginal research officers in Congress





Participatory training

Interviews with peer researchers

Peer-led interviews & debriefing

- Each peer researcher recruited two 'peers' from social networks
- Conducted three thematic interviews with each interviewee
- In between each interview, participated in 'debriefing' interviews
 - data management
 - access youth expert interpretation of findings
 - capability building to strengthen interview technique





Participatory training

Interviews with peer researchers

Peer-led interviews & debriefing

- Youth researchers participated in 'co-design' workshops:
 - review and reflection of data collected
 - design of two trial strategies
 - brain-storming on other ways of increasing STI testing





Navigating complex interactions

...when interviewing people in their social circles:

"happy to share stories and talk about it all ... I couldn't get her to stop talking! She was a good person to interview. I didn't even ask the question but at the end [talking about improving services for young people] she was like, "Oh, we need to improve on this and that"

"shy... more shame... that's just how she is all the time"
"speak the truth... to help young Indigenous people"
"be more patient and encouraging...have space to answer"

(19 year-old woman)





Developed reflective practice

...through review and analysis of their interview recordings, identifying improvements in research skills

"listening to the answers, I think the main thing for me would be to just give them a bit more time... I should just relax in the process. If there's silence, there's silence. It doesn't matter, you know? Let them fill it"

"It was much easier... It just felt like fluid and easy flowing stuff. It was more of a conversation rather than question and answer" (19 year old man)





Interpreting body language

...when engaging young people in conversations about sensitive, rarely discussed topics

"I felt rude asking about it" (16 year-old man)

"I think, just the look on his face, I think he was talking, thinking about what's happened with him... He's looking at the ground and looking really lost and stuff... Maybe he's got drunk and had sex, whatever, and it's happened to him. Maybe." (16 year-old man)





Youth advised & co-designed...

...two strategies to enhance access to STI testing:

Incentive for clinic-based STI testing

- type and value of a suitable incentive
- specific aspects of test, treat and retest cycle to be incentivised
- clinical protocol: timing and location of the offer and distribution of incentives by a clinician to maintain client confidentiality

Remote specimen collection without clinic attendance

 adapted the existing 'Aboriginal Liaison Officer' to ensure a confidential home-based specimen collection process.





Significance of these findings

Young Aboriginal people can and should lead solutions to sexual health

Peer research methodology:

- involves Aboriginal community members who are new to research as co-leaders in health research
- centralises Aboriginal expertise, communication and knowledge in research leading to policy and practice change
- two-way capability building of Aboriginal and non-Indigenous researchers





Future commitment needed

In recognition of Aboriginal people's historical and contemporary experiences of disempowerment in research, offering young people one-off research experiences alone is insufficient:

- more enduring forms of co-investigation beyond one research study
- ensure research qualification to support recognition of skills and future employability

Non-Indigenous researchers to:

- adopt decolonising methodologies and methods
- support Aboriginal communities to lead research
- respect and value two-way exchange
- support systemic change





THANKS!

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