



# Building trust and sharing power for co-creation in Aboriginal health research

**Simone Sherriff**

Project Officer | PhD candidate, The Sax Institute, Australia

**Hilary Miller**

Research and Evaluation Manager, ReachOut Australia





# What is co-creation?

- Working between people or groups who have traditionally been separated into categories of user and producer
- Co-design + co-production / design and creation
- Participatory style of research that recognises inherent social equity power imbalances
- Strengths-based approach to community needs
- Research users (end users) are actively involved and can be transformative for health services
- Values diverse forms of knowledge and experience



# Aboriginal health research in Australia

- A history of research carried out by non-Aboriginal researchers ‘on’ us, not ‘with’ us
- Research agenda set in forums by non-Aboriginal people with no/little input from Aboriginal people
- Large volumes of research were published but not translated into health policy or service delivery – no real benefits for the communities
- Culturally insensitive, deficit-focused
- Researchers have ***“ridden roughshod over our communities, cultures, practices and beliefs”*** – Prof Bronwyn Fredericks
- Co-creation necessary in Aboriginal health research to:
  - recognise power imbalances
  - privilege Aboriginal ways of knowing, thinking and being

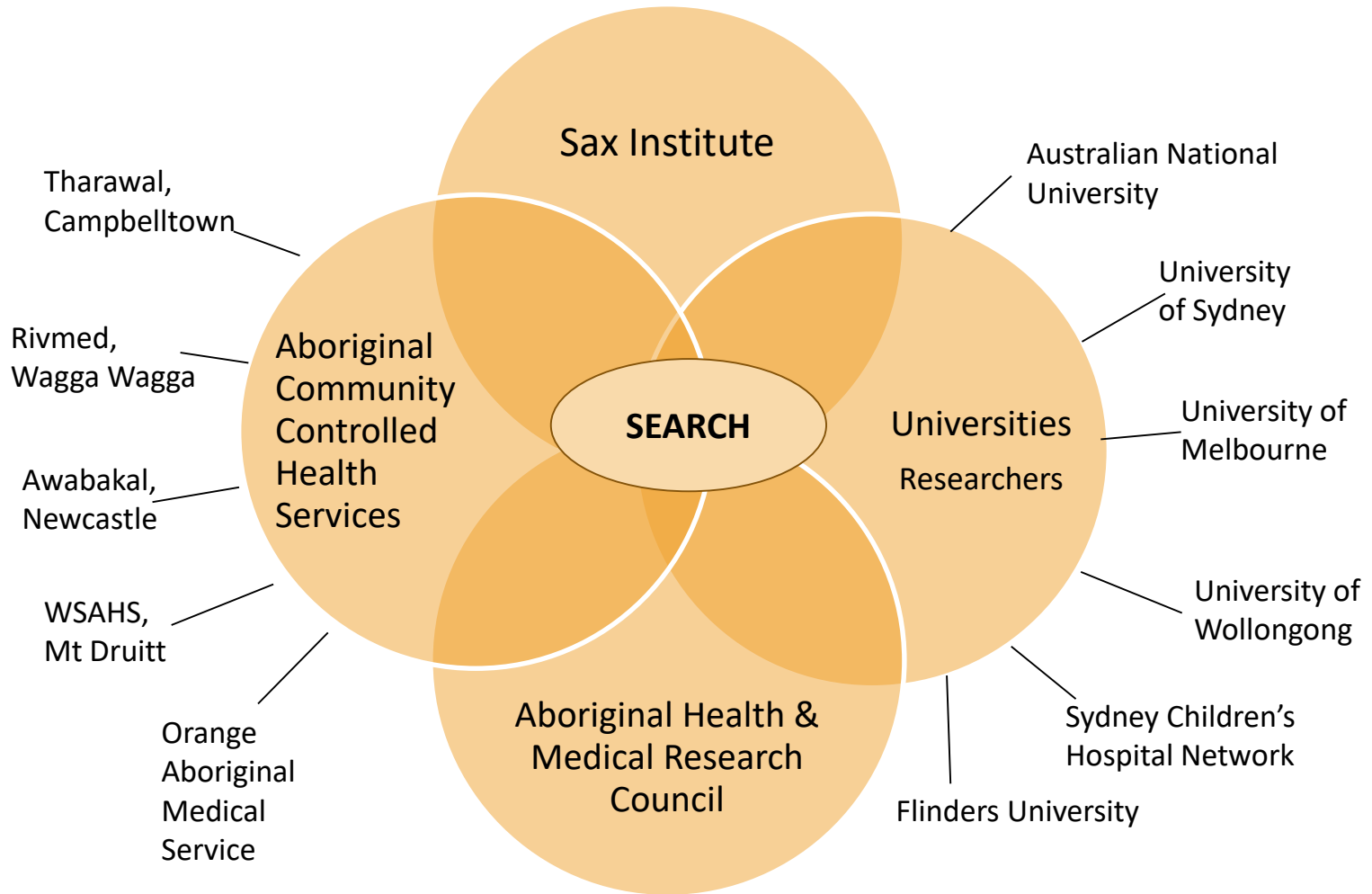


# Study of Environment on Aboriginal Resilience and Child Health (SEARCH)

- Shifting the power to Aboriginal communities driving and leading research
- Largest ongoing study of Aboriginal children in urban areas
- Focuses on improving health outcomes through:
  - expanding programs and services
  - funding for new programs
  - informing policy
  - research capacity building



# SEARCH partnership



# Community priorities



Social and  
emotional  
wellbeing

Obesity,  
exercise,  
green space

Speech and  
development

Child  
health +  
wellbeing

Housing +  
environment

Resilience

Ear health

# Research process

- Since 2008, over 1600 children enrolled in SEARCH from 637 families
- Research is conducted at Aboriginal Community Controlled Health Services (ACCHSs) by local Aboriginal research officers
- Children and families are followed up every 3-5 years
- Longitudinal design allows for identification of factors that may influence health and wellbeing





# Knowledge exchange and research translation

- Data is owned by partner ACCHSs and regularly taken back for interpretation and translations
  - interpretation of data occurs at many levels (e.g. Board, CEO, staff, co-authors)
- An Aboriginal knowledge broker facilitates discussions and assists with local change
- Expert data and knowledge ‘hub’ provides analytic support to ACCHSs
  - identify unmet health needs using SEARCH data
  - advocate for additional funds
  - inform policy
- Data has been used successfully to advocate for programs and additional funding



# Research capacity building

- 32 Aboriginal staff have been given training in research methods and data collection
- 10 Aboriginal researchers working with SEARCH have been supported to complete: post-docs, PhD, Masters, Graduate Diplomas and Diplomas
- 15 Aboriginal researchers have presented SEARCH findings at national conferences
- All papers published from SEARCH have local Aboriginal staff from the ACCHS involved with interpretation of findings, writing and as authors



# Building trust and sharing power for co-creation in Aboriginal health research: a stakeholder interview study

## **Aims:**

- Explore how SEARCH established and continues to build trusting relationships that underpin its successful model of co-creation

## **Interviews:**

- Stakeholders involved in SEARCH (n=26)
  - ACCHSs staff, researchers and policy makers

## **Analysis:**

- Three researchers independently reviewed all transcripts to develop themes
- Workshops were held to compare categories (themes)
- Themes were further defined through analytical discussions with an experienced qualitative researcher



# Results: thematic schema



# Strong foundations (roots)

- **Shared power**

*“the ownership of data is not university owned, researcher owned or Sax [Institute] owned. It's owned by the AMSs and [they] use that data to their best advantage”.*

- **Shared vision, shared goals**

*“if we didn't like each other as people, if we didn't trust what the others were doing, if we didn't think that we all had the intentions and ultimately had the same goal, I think people on both sides would be like, ‘this isn't worth it, it's not worth our time’”.*

- **Strong credible leadership**

*“shared but not uniform”*

*“when you're led by many you have many directions that you need to look at”.*



# Ensuring sustainability (trunk)

- **Willingness to take risks**

*“the relationship is so close because we've honoured each other's agreement in terms of better communication, the release of data, the approval for stuff written up and all that sort of stuff.... [researchers] they've proven themselves”.*

- **Ongoing collaboration and investment**

*“there are no shortcuts to developing trust with people. You have to spend the time and put in the effort and prove again and again why people should trust you”.*

- **Adaptability**

*“Aboriginal people have shared experiences but different interpretations, so data is used differently in each community”.*

- **Valuing local Aboriginal knowledge**

*“the researchers, whether they were Aboriginal or not, had that respect for our community, our culture, and you valued our opinion whether we had a degree or not”.*



# Rewards and outcomes (foliage)

- **Empowering the community**

*“building [research] capability and capacity in communities - you were one of the first studies to do that systematically and to adhere to those principles all the way through the process”.*

*“demystified research”*

- **Connecting across cultures**

*“some researchers think what we want to hear is... ‘Your name will be on the publication’, [but] most blackfellas will go, ‘Shame!’”*

*“it might just simply involve sitting down for a cuppa, and not even talking about the project, because it is about building that trust and that rapport”.*



# Challenges and areas for improvement

- Researchers defaulting to conventional research strategies and using jargon
- Working with different timelines, communication styles, work practices and priorities
- Greater research capacity building for Aboriginal researchers & ACCHS staff
- Researchers could invest more time in relationship building (showing face in community)





# Some principles for building trusting relationships

- Be flexible – one size will not fit all
- Maximise Aboriginal ownership/leadership
- Prioritise relationships
- Develop cultural competency
- Value local community knowledge & expertise
- Clarify who, what and how
- Provide resources and support

# Implications for future research

- Consistent findings with other international literature, some new themes emerged:
  - Strong credible leadership
  - Connecting across cultures
  - Valuing local Aboriginal knowledge and expertise
- Findings reinforce the need for co-creation in Aboriginal health research
- Demonstrate that a co-creation model is achievable and highlight the successes of using one
- Co-creation is essential when working with Aboriginal communities





Aboriginal  
Health & Medical  
Research Council  
of NSW

saxinstitute



Australian  
National  
University

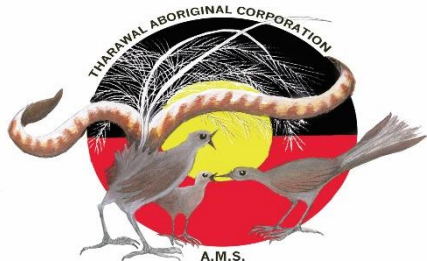


The Australian Prevention  
Partnership Centre  
Systems and solutions for better health



THE UNIVERSITY OF  
SYDNEY

# Acknowledgements



**awabakal**  
OUR PEOPLE

With support from



Australian  
National  
University



Australian Government  
National Health and Medical Research Council



Health



The Sydney  
children's  
Hospitals Network  
care, advocacy, research, education



beyondblue  
the national depression initiative  
[www.beyondblue.org.au](http://www.beyondblue.org.au)