



AIATSIS National Indigenous Research Conference 2019

Research for the 21st Century



INDIGENOUS VOICES AND PRIORITIES IN HEALTHCARE:

**Prioritizing Aboriginal voices through qualitative health research:
an Australian model for focus group research**

Tuesday 2 July 1:30-2.00pm QUT Brisbane

- Prof Kathie Clapham - (UOW)
- Prof Angela Dawson - (UTS)
- Darcelle Douglas - (UOW)
- Joanna Mason - (UOW)





NGARRUWAN
NGADJU

FIRST PEOPLES
HEALTH & WELLBEING
RESEARCH CENTRE

INDIGENOUS LED RESEARCH SUSTAINED
BY STRONG COMMUNITY PARTNERSHIPS



Ngarruwan (the sea across a long distance) Ngadju (freshwater) –
the words bring together the importance of water for sustaining life

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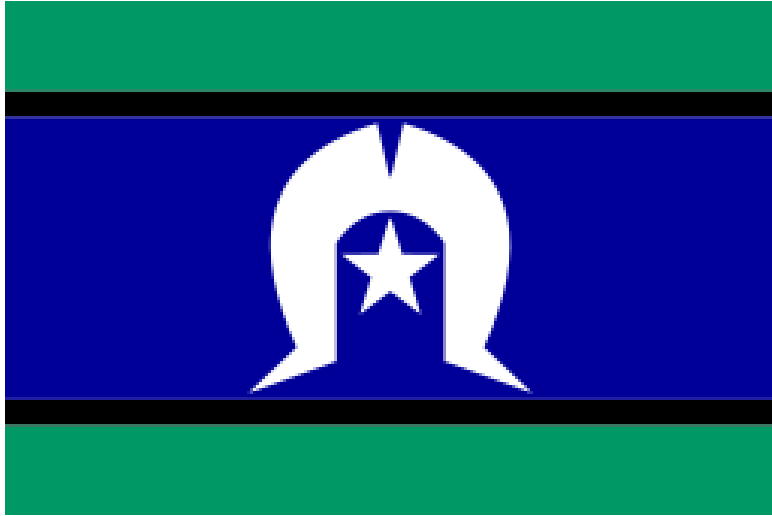
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AUSTRALIAN HEALTH SERVICES RESEARCH INSTITUTE

UNIVERSITY OF
WOLLONGONG

We acknowledge Aboriginal and Torres Strait Islander peoples as the Traditional Owners and Custodians of the land on which we live and work.



<https://ahsri.uow.edu.au/ngarruwan-ngadju/index.html>



We acknowledge the Turrbal and Yugara as the custodians of this land in which we meet today. We pay respects to elders past, present and emerging.

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- NSW Aboriginal Health and Medical Research Council Ethics Committee
- University of Wollongong Human Research Ethics Committee
- Thanks to the study participants
 - Researchers and Policy officers
 - Aboriginal Community Controlled Health Organisations and their staff
 - Cultural and Governance Steering Committee
- Nadia Neal, Pam Grootemaat, Dr Sue McMullan - present and past members of the research team



Three large coloured circles depict:

○ **Aboriginal community**

○ **policy makers**

○ **researchers**

“The emu feet represent the many steps needed for the groups to work cohesively.

The smaller circles represent opportunities and obstacles between policy makers, researcher and the Aboriginal community with a greater need for flexibility.”

‘Emu Land’– Uncle Kevin Butler



Refocus study

ReFocus: The efficacy and appropriateness of Focus Group Discussions for health research in Aboriginal contexts

- ARC Discovery Indigenous Grant
- 2016-2019
- Indigenous led
- Indigenous governance

Aims

- To investigate the way in which FGDs are used in Aboriginal health services research.
- To provide evidence to guide health service planning and delivery which is based on rigorous and culturally appropriate research processes.



Study design

STAGE	PURPOSE	GROUP
Integrated literature review	<ul style="list-style-type: none"> Identify characteristics of FGD studies and inform the study's research questions. 	
1) Exploring multiple perspectives on FGDs and qualitative research	<ul style="list-style-type: none"> Identify how researchers currently employ FGDs in Aboriginal health services research; describe their experiences and needs. Describe the contexts in which FGD and qualitative research evidence has influenced policy; how FGD evidence is valued in decision making. 	<ul style="list-style-type: none"> Researchers Policy makers
2) Listening to Aboriginal voices	<ul style="list-style-type: none"> Explore Aboriginal peoples' experiences of research. Identify how data collection, analysis and dissemination is undertaken in ways that reflect Aboriginal ways of knowing, being, doing. 	<ul style="list-style-type: none"> Aboriginal community, ACCHO staff
3) Knowledge Exchange Forum	<ul style="list-style-type: none"> Bring together researchers, policy makers and Aboriginal community representatives. Develop practical and culturally effective guidelines and resources for FGD research. 	<ul style="list-style-type: none"> All groups

Aboriginal community participants



Focus group participant	n=15
Aboriginal and/or Torres Strait Islander	
Yes	14
No	1
Gender	
Female	13
Male	2
Age	
25-34	3
35-44	2
45-54	2
55-64	3
65+	5
Focus group locations (NSW)	
Urban/Metropolitan	1
Rural/ Regional	1

Recruitment across Aboriginal Community Controlled Health Sector in NSW

Interviewees	n=13
Aboriginal and/or Torres Strait Islander	
Yes	13
No	0
Gender	
Male	10
Female	3
Position	
Health worker	7
Project manager	2
Practice manager	3
CEO	1
Interview locations (NSW)	
Urban/Metropolitan	1
Rural/ Regional	4

Researcher participants



Researchers	n=34
Gender	
Female	28
Male	6
Aboriginal and/or Torres Strait Islander	
Yes	8
No	26
Location	
NSW	16
Rest Australia	18
Type	
Consultant	5
University/research organisation	27
Multiple	2

How we approached this participant group and who we talked to?

- University and government consultants
- Broad representation of Aboriginal researchers
- Purposive sampling
 - project summaries of funded ARC and NHMRC research
 - government contracts, tenders and commissioned research.
 - manual searching of research clearinghouses
- Snowballed to reach data saturation at 34 interviews



Knowledge Exchange Workshop and model development



Today's presentation

Interviews with policy makers:

- What is the use of qualitative research for informing government policy or practice?

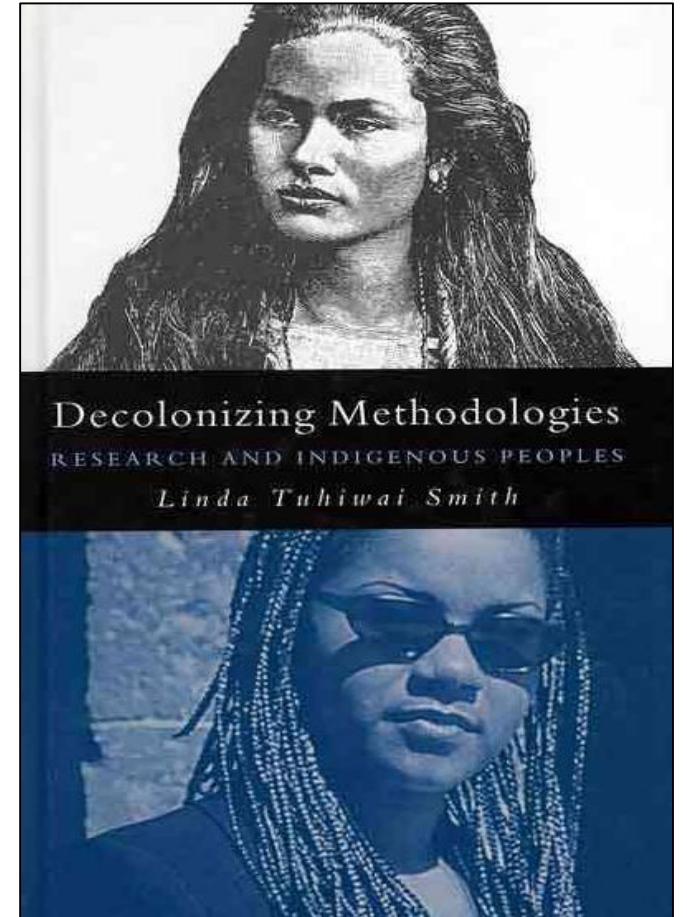
- Explore the capacity of the research sector to meet the needs of Indigenous policy and community into the future.



Indigenous research approach

*“The term ‘research’ is inextricably linked to **European imperialism and colonialism**. The word itself ‘research’, is probably one of the **dirtiest words** in the Indigenous world’s vocabulary... The ways in which scientific research is implicated in the worst excesses of colonialism **remains a powerful remembered history** for many of the world’s colonized peoples... **imperialism** has been perpetuated through the ways in which knowledge about Indigenous peoples was **collected, classified and then represented** in various ways back to the West, and then **through the eyes of the West** back to those who have been colonized”.*

Tuhiwai Smith L. 1999. Decolonizing methodologies: Research and Indigenous Peoples. University of Otago Press. Dunedin, New Zealand.





Policy maker questions

Interviews with policy makers:

- What is the use of qualitative research for informing government policy or practice?
- Explore the capacity of the research sector to meet the needs of Indigenous policy and community into the future.

- Does qualitative research contribute to health policy or decision making, and in what ways does research instill the needs, aspirations and perspectives of Aboriginal people and communities into government processes?



Policy context

- Closing the Gap
 - High level policy agenda
- The Refresh
 - Partnerships and shared decision making

- What is the contribution of qualitative research to informing high level government agendas?
- How does this compare with quantitative research?

Policy maker participants



Policy participants	n=21
Gender	
Female	10
Male	11
Aboriginal and/or Torres Strait Islander	
Yes	5
No	16
Level	
Australian Government	7
State/Territory	7
Local	5
Peak Bodies	2
Position	
Manager	8
Branch Head	3
Director/Deputy Director	7
CEO	1
Policy Officer/Adviser	2

How we approached this participant group and who we talked to?

- 3 levels of government
- Role in policy, commissioning, evaluation, advocacy
- Purposive sampling
 - organisational charts
 - tender documents
- Snowballed to reach data saturation at 21 interviews



Policy makers

- **How** and **why** qualitative research is used
- **Value** of qualitative research and what **impact** has this had
- Capacity to provide **Aboriginal input** into policy making

- How research was **assessed**
- **Improvements** to using qualitative research
- **Strengths** and **limitations** as policy input



Policy makers

- **How** and **why** qualitative research is used
- **Value** of qualitative research and what **impact** has this had

1. To inform government planning and practice
2. As community insight or engagement
3. Conceptual
4. As information, evidence & knowledge



How, why, value, impact

1. To inform government planning and practice

“So qualitative research is absolutely **critical to evaluations** but also to **policy and program design**. ...particularly, in terms of implementation, so **understanding why**; well, understanding the **feasibility and acceptability** of programs, so qualitative research is really important for that” (14)

“The other I suppose, place where qualitative methods are often used is in **formative research to inform program development**” (2)



How, why, value, impact

2. As community insight or engagement

“The objective was to try and better **understand the community views and perceptions** around a particular program and trying to get a richer understanding in terms of the impact that the program is having.” (21)

“So, it’s that qualitative **lived experience** that really shaped what do we need to do differently. We need to **listen to that personal, that collective, hear their story** and how the system isn’t meeting their needs. So, what do we need to do differently?” (11)



How, why, value, impact

3. Conceptual

“Yes. Yes, it has. I am not speaking specifically about health services here. I am thinking more specifically around kind of a **higher level policy understanding** about **what Aboriginal and Torres Strait Islander people value**, which would **inform other stuff down the track.**” (4)

“So we **routinely seek out research** in the areas that are of direct relevance to our policy responsibilities” (1)



How, why, value, impact

4. As information, evidence & knowledge

“...at the policy decision end...and they want some evidence to inform the direction of that, people are kind of **biased towards something quantitative**, because it's neat and succinct and has power. But it's kind of **hard to crow-bar in some qualitative analysis** at that pointy end. But that's not to say that it can't be used **way further back earlier in the story, in the cycle**, when they are trying to identify a gap, or identify where do we go from here, what further research needs to be done, those kinds of **issue identification** style stuff.” (4)



Policy agendas

- policy goals and targets
- aggregate level data & indicators
- accountability
- performance measurement

“The goal of statistical equality, and the **‘evidence based’ methods by which it is to be achieved**, are stated more plainly in Close the Gap rhetoric than in any prior approaches. **The evidence base—quantitative data** based largely upon biomedical and socioeconomic indicators—is the starting point and the guide to action, to the point where **action may only be taken where there are data available to support it.**” (Pholi et al 2009:3)



Research use

- the evidence base
- access to research
- timeliness
- relevance

“one of the things we were conscious of in all of these cases was trying to **get the views of local Aboriginal people** themselves using as rigorous as possible statistical methods but **framing those** or using those, **adjusting those to local context**, because we just didn’t think that the evaluations would have the **credibility** they would otherwise have if you didn’t collect the local voices because you want to **collect the voices** of people who are directly affected, not just base it on outcome data which sometimes can be slow to move, and also a lot of these things are to do with **perceptions** as well so I thought that was really important.” (6)



Representation

- limits to representation
- whose voices

“But one of the things that I found though in indigenous policy is it’s like people so often talk about getting the views of local Aboriginal people, but you sort of think, **but how much effort have you put into actually doing that?** And I wasn’t sure that there was a huge effort in doing that in terms of doing it in a **rigorous systematic way.**”
(6)



Versus quantitative

- best method for purpose
- mixed methods

“Certainly in this example, if it had been only qualitative research, it would not have been useful at all because you are looking at rate comparisons ... We are trying to move towards things that are a **quantifiable goal**. And, because of that, you need the quant component as well. So a qualitative study that has maybe got together...a bunch of interviews or a case serieswould **not have been very compelling evidence**. Interesting but not compelling....And you need some evidence that it’s something that will have a **widespread effect**. You have a case series of half a dozen kids, you are trying to say well, that’s fine for those kids but that doesn’t give me a huge kind of volume of evidence to argue for it to be a generalised concept.” (20)



Improvements

- within policy and government
- research literacy
- quality and rigour of qual studies

“...starting to get to a place where there's some **greater understanding** amongst researchers about what policy makers' needs are and also, policy makers' increased understanding of how research is generated as well. **So, it goes both ways.** You need building capability capacity in both of those arenas is really important. Otherwise, researchers will **continue to generate things that are interesting** and so on, but has **no relevance to the business of government** in terms of changing policies or providing services.” (3)



Conclusions

- range of valid uses of qualitative research
- understand research conduct and use
- appreciate different worldviews
- direct accountability and connection
- research benefit

“...because our overarching goal is to **close the gap** in Indigenous health across all sorts of spectrums and wanting – and we’re not doing that as well as we would like, so we’re **interested in anything, really, that can tell us why we’re not doing that**, or how we can get more traction with the way in which we’re spending, so that we can make sure that our investment is well-targeted and that our programs are well-designed.” (5)

“...there’s definitely been times when we’ve ...said, “No, that’s inappropriate,” or that isn’t for us, but it’s taken us a long time to be confident to be able to go, “hold on a second, **why is this research being done, what is for? How will it benefit our community?**” (Community interview)

Thank you

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Reference:

Pholi, K., 2009. Is 'Close the Gap' a useful approach to improving the health and wellbeing of Indigenous Australians?. *Australian Review of Public Affairs: Journal*, 9(2).