



“It can help our community... I hope the government will listen to what we are saying”

Reasons for caregiver participation in a longitudinal study of Indigenous Australian children

OUTLINE

Research rationale and aims

Analytical methods

Findings and implications

Reflection on AFPHM competencies

Indigenous health and research participation

Aboriginal and Torres Strait Islander (Indigenous) people

- 3% of the Australian population
- Diversity of cultures and languages spoken
- Great resilience following the impacts of European invasion

Critical to engage Indigenous communities in health research, but issues exist^{1,2,3}

Historical
context of
research
involving
Indigenous
people

Major factor influencing
recruitment and retention

For the benefit of non-Indigenous
parties in the majority of cases^{2,4}

Government-led research
particularly problematic due to past
policies⁵⁻⁷

Reasons for participation

- Large scale studies involving Indigenous people exist – including government-led
- Two small Australian studies have previously investigated reasons for Indigenous participation in research^{2,8}
- Found that participants are motivated by:
 - Opportunities to contribute data which tells their story
 - Perceived benefits for their communities and future generations



My aim?

To explore perceived community benefits to contributing information in a longitudinal study of Indigenous children, and the apparent role of government in enabling or impeding these benefits

The Longitudinal Study of Indigenous Children (LSIC)⁹

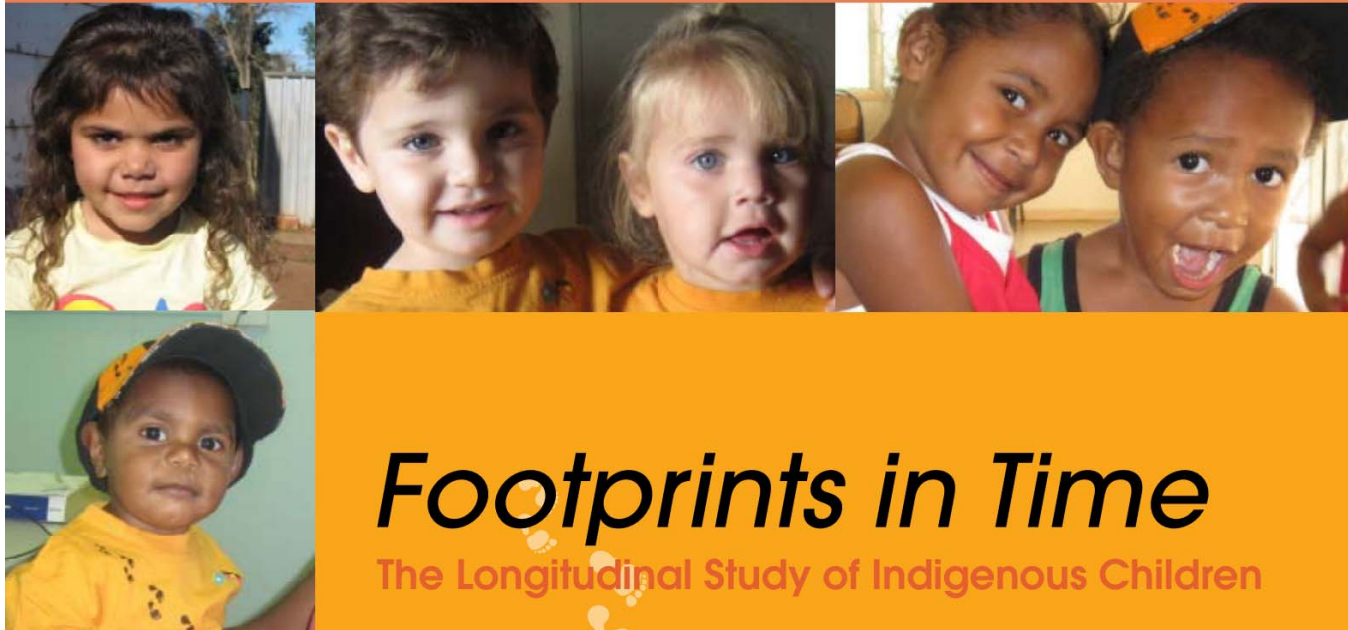
- Run by DSS
- Large diverse sample of Indigenous children and their families
- Annual waves since 2008
- Face to face interviews with Indigenous research officers
- Topics such as culture, parenting, education and wellbeing
- Majority quantitative data, but includes responses to open-ended questions
- High retention rate – 70.7% in Wave 6¹⁰



Footprints in Time



Australian Government



Analytical methods

- 1,239 primary caregivers in Wave 6 were asked '*Why do you stay in the study? What do you like about Footprints in Time?*'
 - 1,133 valid responses (91.5%)
- Qualitative methods: conventional content analysis¹¹ and manifest analysis¹²
- Initial analysis by three independent researchers identified eight key themes in sub-sample of 160
- Further analysis of two themes (**'community benefit'** and **'telling our story'**), plus third concept of interest (**'government'**) using full sample of 1,133 responses

Total participants in any wave (1,752)

Wave 6
(n = 1,239: 70.7%)

Lost to follow
up
(n=520: 29.3%)

Response to study question
(n=1,133: 91.5%)

No response
(n=106: 8.5%)

**Community
benefit**

(n=223: 19.7%)

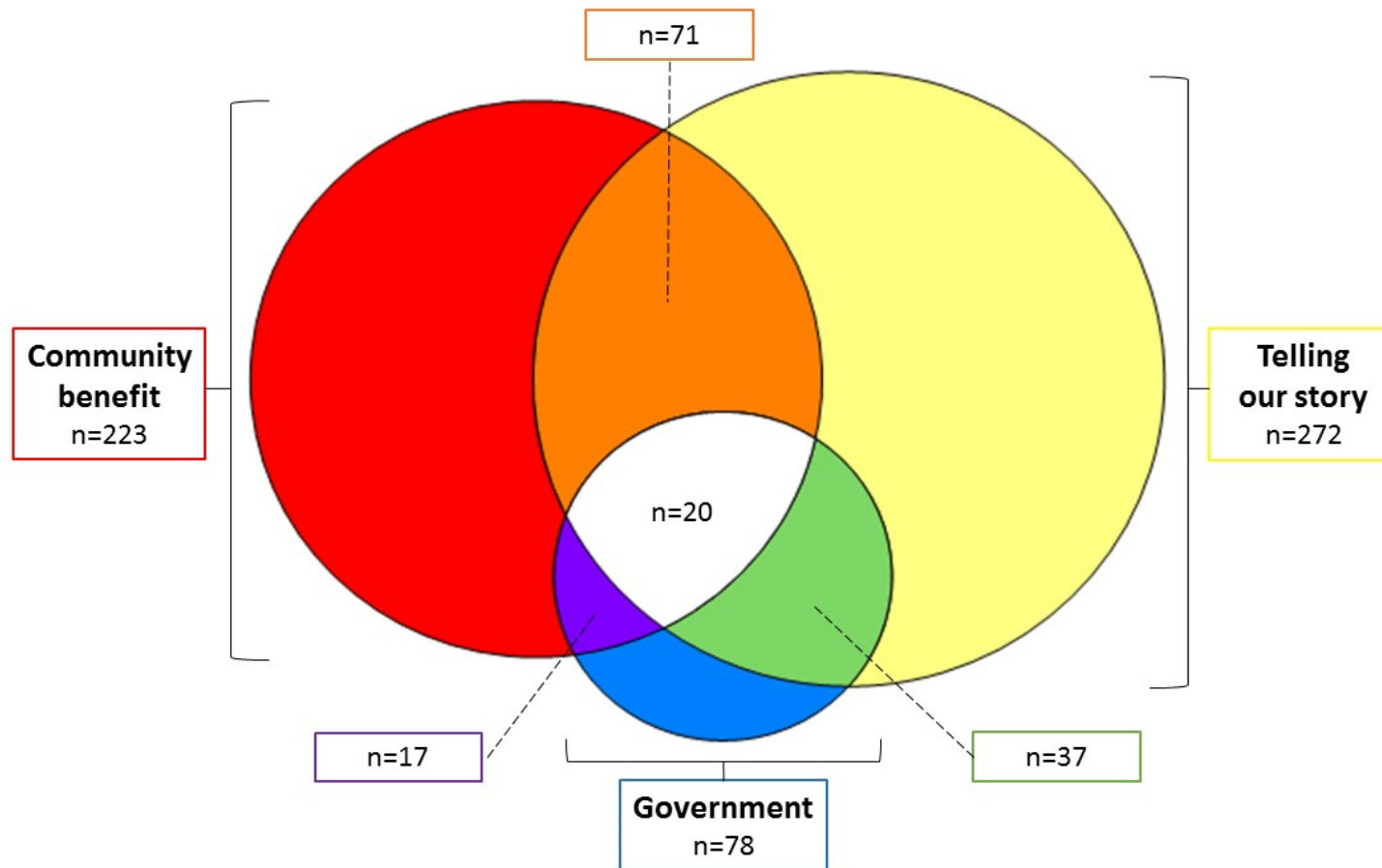
**Telling our
story**

(n=272: 24%)

Government

(n=78: 6.9%)

Relationship between themes



Relationship between themes

- 'Telling our story' and 'community benefit' most commonly co-occurring themes (n=91, 8% of total)

... the hope that something good might come and insights into Indigenous are used in a helpful way, not against them. It needs to be supportive, not detrimental, not negative.

... I think the study is useful for the future, our kids are our future and if we don't get studies then we don't have the proof.

I want our culture to stay strong and the only way to do that is to record the information that is out there.

Relationship between themes

- Link between two themes often through the third theme of 'government'

Hoping it will help the government to use the information that parents are giving to provide better services to the Indigenous community.

It's good to collect data, also to provide the study with information that can help families not have their children taken off them.

... the government need to listen more... [they] take a long time to do anything for this community.

- Importance of community consultation^{3,6,13}
- Recording stories as part of healing past traumas and rebuilding trust⁶

Strengths and limitations



- Large sample size (prev. n=8, n=160)
- Broad diversity across Australia and all levels of remoteness
- Over 90% response rate to study question
- Input from Aboriginal researchers at all stages
- Perspectives from primary caregiver only
- Responses transcribed by research offers to free text responses
- No data on what caregivers did not like or what they would change

Conclusions

- Enduring legacy of historical traumas
 - BUT, assumptions re: reluctance to engage neither useful nor accurate
- The right approach is essential
 1. Government giving opportunities to contribute personally meaningful information
 2. Government listening to these contributions
 3. Initiatives must be designed to genuinely benefit Indigenous communities
- Understanding reasons why Indigenous people participate in research will promote research that is ethical, facilitates trust, and produces meaningful information for Indigenous communities as well as the wider Australian society





AFPHEM Competencies

- **Public health research and teaching (3.2)**
 - Design and conduct effective research studies (3.2.1)
 - Use qualitative methods to investigate public health issues (3.2.8)
- **Public health information and critical appraisal (3.1)**
 - Critically assess published literature and other evidence (3.1.5)



AFPHM Competencies

- **Universal cultural competencies (2.1)**
 - Manage one's own cultural competence development (2.1.1)
 - Plan, analyse, research and evaluate public health issues in a culturally competent manner (2.1.4)
 - Develop and implement policy, proposals and programs from a culturally competent perspective (2.1.5)
- **Aboriginal and Torres Strait Islander health (2.3)**
 - Analyse public health issues based on the perspective, rights and status of Aboriginal and Torres Strait Islander peoples (2.3.1)
 - Advise on public health issues for Aboriginal and Torres Strait Islander peoples (2.3.2)



Acknowledgements

Thank you to the other members of my research team:

Dr Katie Thurber

ANU NCEPH, supported by Lowitja Institute

Dr Raymond Lovett

ANU NCEPH, supported by Australian NHMRC

Andrew Hunter

ANU Medical School

ACT AFPHM fellows for feedback

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Questions?