'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

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Background: To improve health outcomes for Indigenous Australians, it is critical to improve collection and interpretation of data through the engagement of Indigenous communities in health research ¹⁻³. Despite this, there is a persistent perception among researchers that research involving Indigenous people is difficult ^{1,4}. Furthermore, factors such as historically exploitative research practices and discriminatory government policy can influence Indigenous peoples' willingness to participate in research ^{1,4,5}. The aim of this paper was to explore Indigenous Australians' views and experiences of participating in a longitudinal study of Indigenous children, and in particular why they participate.

Methods: A conventional content analysis was applied to 1,133 free-text responses to the question, 'Why do you stay in the study? What do you like about Footprints in Time?', asked of caregivers participating in Wave 6 of the Longitudinal Study of Indigenous Children (LSIC). An inductive qualitative approach was applied to identify themes, followed by assessment of frequency and co-occurrence of these themes.

Results: Three themes – 'community benefit', contributing information ('telling our story') and 'government action' were identified. Many (20%) perceived that participating in the study has the potential to benefit Indigenous Australians. It was common for participants (24%) to state that by contributing their information, they were assisting researchers to record important information about Indigenous life. Linking these two themes, some participants (7%) also articulated a hope that the government would listen to their stories, and use the study information to evidence the design and implementation of initiatives which could benefit communities and future generations of Indigenous people. There was a substantial co-occurrence of these themes (12.8% of responses included at least two themes, and 1.8% included all three themes).

Conclusion: In this cohort of 1,133 caregivers of Aboriginal and Torres Strait Islander children, we found that many caregivers were willing to contribute information to government when they perceived that this would meaningfully benefit their communities and future generations. The findings of this study suggest that despite perceived barriers in conducting research with Indigenous Australians, research participants commonly report that it is worthwhile participating in research because they feel that they are contributing to the consolidation of knowledge and that this information can influence change.

References:

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¹ Guillemin M, Gillam L, Barnard E, Stewart P, Walker H, Rosenthal D. "We're checking them out": Indigenous and non-Indigenous research participants' accounts of deciding to be involved in research. Int J Equity Health. 2016;15(1):1-8.

² National Health & Medical Research Council. Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research. Canberra: Commonwealth of Australia; 2003.

³ Australian Indigenous HealthInfoNet. Overview of Aboriginal and Torres Strait Islander health status 2016. Perth: Australian Indigenous HealthInfoNet; 2017.

⁴ Grove N, Brough M, Canuto C, Dobson A. Aboriginal and Torres Strait Islander health research and the conduct of longitudinal studies: issues for debate. Aust NZ J Public Health. 2003; 27(6):637-41.

⁵Lawrance M, Sayers SM, Singh GR. Challenges and strategies for cohort retention and data collection in an indigenous population: Australian Aboriginal Birth Cohort. BMC Med Res Methodol. 2014;14:31.