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Staying Deadly Pilot Study – Findings

Background

The Queensland Urban Indigenous Mental Health Survey / The Staying Deadly Survey is a mental health survey that is helping us find out how many of our mob are living with mental disorders, what mental health services they use, and what are the barriers to accessing care. Although there have been two national studies on mental health, none of these have looked specifically at Aboriginal and/or Torres Strait Islander mental health. This is the first time this kind of research has been done with Aboriginal and/or Torres Strait Islander people living in an urban community in South East Queensland.

The Staying Deadly Pilot Study was conducted with a group of 42 Aboriginal and/or Torres Strait Islander people. The pilot study was an opportunity for the research team to test the survey materials and methods, and get feedback from participants about what could be improved for the main survey. This summary gives an overview of the results from the pilot, and the next steps forward towards the main survey.

Preparation

The pilot study research has been approved by two ethics boards; Townsville Human Research Ethics Committee (HREC), and the University of Queensland HREC. Community consultation was sought at all stages of the project in order to provide guidance on culturally appropriate ways of conducting this kind of research. Community consultation took various forms, including: round-table meetings, briefing meetings, steering committee meetings, preliminary testing feedback, and participant feedback. Community consultation will continue and be ongoing for the main survey.

Pilot Study

The pilot study ran for 10 weeks between September and November 2019. By the end, 62 participants had expressed an interest in participating in the survey. Of these, 56 were booked in for a survey appointment, with 42 participants attending.

Findings

The study methods were appropriate and acceptable for delivery of the main survey

The pilot study methods and processes were largely successful, with most participants reporting positive experiences with no major issues other than length and repetitiveness of the survey. We learned that the relationships between the interviewers and participants, and the relationships between the interviewers themselves, were important in creating positive experiences and helped participants to complete the survey. Participants also said they liked the acknowledgement gifts they received for participating (the Staying Deadly Jersey/\$25 Coles/Myer gift card).

Participants were happy with the cultural suitability of the survey instrument and how it was delivered

The research team asked participants about their personal and cultural perspectives about the survey experience. This was through a feedback form, and/or through discussions with the survey staff. Overall, participant experiences and responses to the survey were positive. People overwhelmingly reported feeling comfortable and happy to do the survey as a whole. Despite the structured format and some survey questions containing blunt or direct questions about sensitive and difficult issues, almost all the feedback indicated that participants reported feeling safe and supported throughout the survey, even though some of the questions were hard to answer. Many participants told us that they

believe this research is important for mob and worth doing. Participants also praised and spoke about the importance of having Indigenous survey interviewers. There was also feedback about areas for improvement, with the most comments made about both survey length and repetitive questions.

The survey instrument (the CIDI 3.0) varied in its usefulness

The CIDI 3.0 (Composite International Diagnostic Interview 3.0) is a standardised survey instrument that can diagnose mental and substance use disorders in the general population, but has not been tested fully in an Indigenous Australian population. The Staying Deadly research team tested the CIDI 3.0 by comparing its diagnoses with the diagnoses provided by our Staying Deadly Indigenous clinical psychologists. We learned that the CIDI 3.0 had some use in identifying the presence of mood disorders and post-traumatic stress disorder, and is likely to be able to identify generalised anxiety disorder. Notably, the CIDI 3.0 overestimated the amount of people diagnosed with mania. This may be explained by cultural differences in how Aboriginal and Torres Strait Islander people express depression, which the CIDI 3.0 instrument misattributed to symptoms of mania.

Learnings and next steps

Based on participant feedback, community consultation and study results, there will be several improvements made to the main survey. Some of these include:

- Reducing the length of the survey by reducing the number of questions
- Making the survey less repetitive by combining and removing questions
- Removing the Mania module of the CIDI 3.0 as it was not useful for our pilot participants
- Recognising that participants and interviewers may feel more comfortable discussing sensitive issues with someone who is the same gender as them, and trying to accommodate this wherever possible
- Although the interview is ideally conducted in a private space, some participants wish to have support persons present, or may have children with them at the time of interview

The main survey aims to recruit a much larger group of survey participants so that we can draw population-level conclusions about mental and substance use disorder prevalence and service use in urban residing Aboriginal and/or Torres Strait Islander people. We hope our findings will help us better understand and advocate for the need for mental health services for Aboriginal and/or Torres Strait Islander people in South-East Queensland. The main survey is due to commence in the second quarter of 2020.

The Staying Deadly Survey is a collaboration between the Department of Health, Queensland Centre for Mental Health Research, the Institute for Urban Indigenous Health and its member services. If you have any questions about the pilot study findings, or would like to learn more about the Staying Deadly survey, please email us at stayingdeadly@gcmhr.uq.edu.au.