



the  
**Lowitja**  
Institute

Australia's National Institute for Aboriginal and  
Torres Strait Islander Health Research

**ETHICS CASE STUDY: JULY 2015**

## Towards the development of a wellbeing model for Aboriginal and Torres Strait Islander peoples living with chronic disease

**A South Australian Health and Medical Research Institute project**

The wellbeing study developed a framework to assist primary health care services support the wellbeing of Aboriginal and Torres Strait Islander peoples living with chronic disease.

### Background

The Wellbeing Study was undertaken as a **direct result of concerns raised by community members** who participated in a qualitative study that explored what care means for Aboriginal and Torres Strait Islander Australians and how people experience, cope with and adapt to life-long illnesses. This study identified important questions about whether existing chronic care models are either acceptable to Aboriginal and Torres Strait Islander peoples or effective in managing chronic disease.

It was undertaken by a national reference group consisting of community Elders, Aboriginal Medical Service staff and policymakers, as well as a team of researchers that included 13 Aboriginal and Torres Strait Islander health professionals from across Australia. More than 70 Aboriginal and Torres Strait Islander community members and health care practitioners who provide care to Aboriginal and Torres Strait Islander people reviewed and advised prior to release of the wellbeing framework.

### Why is the project an example of good practice in Aboriginal and Torres Strait Islander ethics?

*This project strongly demonstrates ongoing engagement, collaboration and partnership with the Aboriginal and Torres Strait Islander community. It included capacity building and professional development for Aboriginal and Torres Strait Islander people and demonstrated a high level of research translation to ensure stakeholder involvement at every stage of the research.*

The Wellbeing Study is part of a national program of research led by the Kanyini Vascular Collaboration (KVC). The KVC represents a **long-term partnership of senior Aboriginal and Torres Strait Islander and non-Indigenous researchers**. The partnership is committed to engaging Aboriginal and Torres Strait Islander community members **from the earliest stages of research planning right through to the dissemination of research findings** in order to facilitate greater participation and understanding of the research agenda, aims and findings.



**EthicsHub** is an online resource to support people and organisations working or participating in Aboriginal and Torres Strait Islander health research.

[www.lowitja.org.au/ethics](http://www.lowitja.org.au/ethics)

For the Wellbeing Study this included, but was not limited to, a research team comprised almost entirely of Aboriginal and Torres Strait Islander people. **Led by a senior Aboriginal researcher, the team also included 13 Aboriginal and Torres Strait Islander Research Fellows from seven Aboriginal Medical Services, as well as two Aboriginal researchers, one of whom is an Aboriginal PhD candidate, and three non-Indigenous researchers.**

The Research Fellows, who had extensive health care knowledge but were relatively new to research, attended two master classes focusing on ethical research and qualitative research methodology as part of this study.

Aboriginal researchers were instrumental in co-facilitating the qualitative data collection and in analysing and interpreting the interview transcripts for this study, and also **actively shaped the research processes and clarified its outcomes.** They were also included as authors on all publications and presentations resulting from this study.

The three-stage study first reviewed published literature, then consulted community members and primary health care practitioners to identify ways in which services could support the physical, emotional, social, spiritual and cultural wellbeing of Aboriginal and Torres Strait Islander people living with chronic disease. Finally, through significant consultation with our reference group, consensus for a wellbeing framework was reached.

Community members and Aboriginal Medical Service staff were also involved in the consultation process undertaken as part of the Wellbeing Study. A total of 72 community members and health care providers from seven Aboriginal Medical Services in the Northern Territory, Queensland, New South Wales, ACT, South Australia and Western Australia participated in the consultation.

*The study involved developing equal partnerships with Aboriginal and Torres Strait Islander communities and involved extensive consultation and input from these communities. Community members ultimately determined what they wanted from the study and how it would benefit Aboriginal and Torres Strait Islander people. – Wellbeing Study Research Fellow*

The Wellbeing Study team provided a number of face-to-face presentations to staff and community members at these services, and supported the Wellbeing Study Research Fellows on-site throughout the data collection phase of the study. As members of the research team, the Research Fellows were full partners in this study. The Stage 3 consultations provided opportunities for community members and health care providers to have direct input into the research project that aimed to improve primary health care services for Aboriginal and Torres Strait Islander people living with chronic disease.

By involving both Aboriginal and Torres Strait Islander and non-Indigenous stakeholders in the National Reference Group, the study provided many opportunities for ongoing two-way learning.

*I found the Wellbeing Study to be a valuable learning experience both personally and professionally. I had not previously had the opportunity to be a part of something like this and found it to be a great learning experience. I was pleasantly surprised with the research process, particularly the depth of consultation and the how intrinsic cultural safety was at all times. – Wellbeing Study Research Fellow*

The Wellbeing Study Research Fellows were invited to represent the project at the National Reference Group Consensus Workshop, to feedback the research findings to participating health care services, and will be acknowledged as co-authors on all publications resulting from this study. The study has also provided each Research Fellow with a year's subscription to *Australian Journal of Primary Health Care* and has collaborated with the Primary Health Care Research Information Service (PHCRIS) to fund six Research Fellows to present at the 2015 PHCRIS Conference.

The study team is arranging regular newsletters and teleconferences with the Wellbeing Study Research Fellows throughout 2015, as well as seeking to fund further face-to-face research team meetings into the future.

*[As health workers], we have existing lines of contact, and many participants are interested in how the study is progressing since the data collection stage. We can maintain reciprocity by continually feeding back information as we receive it from the Team. – Wellbeing Study Research Fellow*

**The Lowitja Institute**  
PO Box 650, Carlton Vic 3053  
t: +61 3 8341 5555  
f: +61 3 8341 5599  
e: admin@lowitja.org.au  
[www.lowitja.org.au](http://www.lowitja.org.au)

