



the  
**Lowitja**  
Institute

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

**ETHICS CASE STUDY: JULY 2015**

## Next steps for Aboriginal health research

**An Aboriginal Health Council of South Australia (AHCSA) project in partnership with the South Australian Health and Medical Research Institute (SAHMRI)**

The project aimed to identify and prioritise the main health and medical research areas that align with the needs and interests of Aboriginal people within the Aboriginal Community Controlled Health Organisations, Aboriginal Health Advisory Councils and the Aboriginal community in South Australia.

### Background

Phase one included a literature review; preliminary audit of Aboriginal Health Research Ethics Committee database (AHREC) and AHREC approval; engagement with the AHCSA Board, Aboriginal Community Controlled Health Organisations (ACCHOs) and Aboriginal Health Advisory Councils (AHACs) that continued throughout the project. Phase one also included the establishment of the co-investigators group and training to support their oversight of data analysis; the signing of the first consultancy agreement between AHCSA and South Australian Health and Medical Research Institute, employment of an Aboriginal Research Officer, and conducting 59 interviews with staff from ACCHOs and AHAC members.

Phase two involved the signing of a further consultancy agreement between AHCSA and SAHMRI, analysing the data from interviews, gaining AHREC approval for a modification, conducting a second audit of the AHREC database, and holding the Consensus Workshop.

### 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 and has included capacity building and professional development for Aboriginal and Torres Strait Islander people. The project has also demonstrated a high level of research translation to ensure stakeholder involvement at every stage of the research.*

The purpose of the project was to reclaim the research agenda to focus on **topics of priority for the Aboriginal community**. It also empowers ACCHOs, who are frequently approached to provide support for research.

The origins of this project date back to 1986, when AHREC became the first Aboriginal Human Research Ethics Committee in Australia as research had been going unchecked in Aboriginal communities.



**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)

The establishment of SAHMRI and the Wardliparingga Aboriginal Research Unit provided an opportunity to build upon AHREC concerns and the IHRSS recommendations by **conducting a comprehensive review of community priorities for research**. The project became the first project undertaken in partnership between AHCSA and SAHMRI's Wardliparingga Aboriginal Research, led by Professor Alex Brown.

There was **ongoing communication and engagement** with members of the South Australian Aboriginal community from the outset to completion of this project.

A member of AHREC since 1986, Isabel Norvill, a Kurna–Ngarindjerri woman said,

*I just hope that now all research will involve Aboriginal people themselves.*

Professor Alex Brown and Ms Kim Morey (Wardliparingga Aboriginal Research Unit) were members of the research team and this unit **supplemented the project with staff and training, as needed**. At the core of this study was the engagement with, and participation of, a range of staff who work in ACCHOs, including CEOs, senior managers and Aboriginal health workers.

An **Aboriginal Research Officer was employed** at AHCSA to coordinate the project. The officer also undertook and graduated from the Certificate IV in Indigenous Research Capacity Building course convened at AHCSA.

Seven co-investigators were invited from ACCHOs and from within AHCSA staff to **steer the project and advise the investigators** on participant recruitment, data collection, data analysis and dissemination of the results and to promote the aims and objectives of the project. They were provided with training on how to analyse qualitative data. The input and perspectives of the AHACs and ACCHOs were fundamental and formed a crucial link with Aboriginal communities in formulating an **Aboriginal-centred knowledge base** for the development of health and medical research priorities and for informing approaches to the **proper conduct of research with and for Aboriginal people**.

Towards completion, the Consensus Workshop held in Adelaide was attended by 37 representatives, including ACCHOs (n=12) and AHACs (n=12). Attendees included Aboriginal community representative through to ACCHO CEOs. The **research was translated** with the main findings presented to attendees; it produced high level themes and a **final list of research topics for the ACCHO sector** reflecting both local and state-wide priorities.

One of the seven recommendations in the report states that researchers, universities and research institutes should utilise the key findings of the Next Steps study to guide the development and delivery of research that aims to improve the health and wellbeing of Aboriginal people in South Australia.

A second **recommendation is for the production of user-friendly resources** for wide dissemination across the ACCHO sector, AHACs, universities, research institutes, South Australia Health, the National Health and Medical Research Council (NHMRC) and other relevant bodies.

The final report and community brochure artwork produced by Aboriginal artist, Anna Dowling states:

*Thousands of fibres are connected together to form one strong body and I see this as a reflection of the Next Steps project which brings together thousands of pieces of information and stories from the voices of Aboriginal South Australians to paint the picture of what Aboriginal health research should look like.*

## Project timeline:

**Phase one:** November 2012 to December 2013  
AHREC approval granted November 2012  
First consultancy agreement between AHCSA and SAHMRI in February 2013  
Employment of an Aboriginal Research Officer in May 2013  
59 interviews with staff from ACCHOs and AHAC members Nov 2012–Dec 2013

**Phase two:** January to May 2014  
Second consultancy agreement between AHCSA and SAHMRI in January 2014  
Second audit of the AHREC database in March 2014  
Holding the Consensus Workshop in April 2014.

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