Next Steps for Aboriginal Health Research

Exploring how research can improve the health and wellbeing of Aboriginal people in South Australia

Community Report
February 2015

Research Background

The main driving force behind the Next Steps project was to reclaim the research agenda back from research topics defined by the research sector, to topics of priority for the South Australian Aboriginal community. This project supports self-determination through improved targeting of research priorities, defined by Aboriginal and non-Aboriginal people who work in the 11 South Australian Aboriginal Community Controlled Health Organisations (ACCHOs).

Three key developments provided an important background to this project:

1. In 1986, the Aboriginal Health Research Ethics Committee (AHREC) formed, to function as an independent sub-committee of the Aboriginal Health Council of South Australia (AHCSA). AHREC formed out of concerns to control research activity proceeding unchecked in Aboriginal communities.

2. In 2005, AHCSA commissioned the 'Indigenous Health Research Scoping Study' (IHRSS) (AHCSA, 2005), to report issues related to Aboriginal health research in South Australia.

3. In 2012, the South Australian Health and Medical Research Institute (SAHMRI) was founded and provided an opportunity to build upon AHREC concerns and the IHRSS recommendations.

Next Steps was the first project undertaken in partnership between AHCSA and SAHMRI. This project was funded by SAHMRI and based at AHCSA. Additional funding was provided by the Lowitja Institute.

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Aim

To identify and prioritise the main health and medical research areas that align with the needs and interests of Aboriginal people within the ACCHOs, Aboriginal Health Advisory Committees (AHACs)[1] and the Aboriginal community in South Australia.

How the research was done

The Next Steps project began in November 2012 and was completed in April 2014. The methodology included two audits of the AHREC database, semi-structured face-to-face interviews (N=59) and a Consensus Workshop (N=37). Ethics approval was provided by the AHREC.

What we found

The Next Steps model identifies five main health and medical research priority areas. Health and wellbeing research needs to:

- Utilise approaches that respect and engage with a view of life that is holistic and interconnected
- Focus on people's everyday health and wellbeing needs in real life contexts across the lifespan
- Develop an understanding of resilience, diversity and unique community needs
- Be driven by and involve Aboriginal and Torres Strait Islander people
- Provide a tangible benefit back to community
- Be translated into policy and practice.

Aboriginal health is holistic and interconnected

Strong and healthy babies, children and young people

Healthy women and men for families and community

Understanding and recognition of Aboriginal resilience, diversity and unique community needs

Sustainable ACCHOs and Aboriginal health workforce doing research and delivering healthcare across South Australia

Model of five main health and medical research priority areas

Aboriginal health is holistic and interconnected

> *And – and if you squeeze one thing, you've got to look at what you can provide knowing full well that if you don't do the whole stuff it's actually going to be a bit of a drop in the ocean.*
> Interviewee

Research into Aboriginal health and wellbeing needs to take into consideration the interconnectedness between cultural, spiritual, social and physical factors across the life span. This is a foundational priority. Research topics that are of particular interest, need to be explored within real life contexts. Research into housing, education, employment, social networks, connection with land, racism and law enforcement is needed.

Strong and healthy babies, children and young people

> *If there is one thing I would change it would be for our next generation, getting our young people to stand up and walk side by side with anyone – that our kids aren't left behind.*
> Interviewee

A key research priority area is building 'our next generation' by focusing on Aboriginal babies and children up to 14 years' of age, including mothers' antenatal care and ensuring the health and wellbeing of young people (aged 15 to 24). Specific priority areas include factors that contribute to thriving infants (up to three years' of age), foetal alcohol syndrome, nutrition, women smoking and/or drinking alcohol during pregnancy, maternal health and the social and emotional wellbeing of mothers, and the role of fathers in child care and rearing. A critical area of research is the need to know more about the disproportionate levels of suicide among young Aboriginal people, identification of critical intervention opportunities and the composition of culturally appropriate support services.

[1] *During the period of conducting this research, the AHACs were fully operational and contributed to this study. However, in October 2014, Country Health SA Local Health Network announced dissolution of the AHACs.*

Healthy women and men for families and community

> ...if you are an Aboriginal woman...your unborn child, is at risk and ...you need to be in a major hospital to give birth...the expectant mothers are putting off their...antenatal checks for their desire is not to be hospitalised in the city...(many) kilometres (from home)...bereft of family...the disconnect from the father...is massive...I can't see how you can have healthy communities without having healthy mothers and healthy babies...
> Interviewee

> ...they go on their fathers and sons camp (and)...(a father) didn't know what to do 'cause (his child was) hyperactive, so the camp was really good because it gave that young father an opportunity to be with other men, so they're able to build support in a camp, (because) they're all there together.
> Interviewee

Women, as mothers and carers of children, and the general health of men featured as two specific topics. Research is needed to help support and grow a male Aboriginal health workforce, to provide culturally appropriate services, greater gender balance and to contribute to better health outcomes for Aboriginal men.

Understanding and recognition of Aboriginal resilience, diversity and unique community needs

> They've been out on country having visits and doing some of that caring for country work... they are really building a strength about what is a dad's role and a grandfather's and uncle's role in supporting each other, and that brother care about if things aren't going too well, what can we be doing?
> Interviewee

This priority area included strong concerns about the impact, prevalence and treatment of these health conditions: diabetes, cancer, cardiovascular disease, adult and childhood obesity, childhood illnesses and chronic disease onset, blood borne viruses, co-morbidities and multi-morbidities and human immunodeficiency viruses. Some communities described overwhelming impacts of health conditions on individual and community resilience. Each community has unique needs and this contributes to substantial differences in the social determinants of health, the availability of food and food choices, and Aboriginal empowerment and leadership.

Sustainable ACCHOs and Aboriginal health workforce doing research and delivering healthcare across South Australia

> ...our (ACCHO) was set up by local people (who) were... driving that process...we've been able to set the direction for the organisation through having that local input, local knowledge and working together with community... And one of the best things about Aboriginal community control, it's about self-determination... We develop it with the community. So when we start a process, if the community's involved, as we work through it we get to a stage where we're able to deliver the service. We've educated the community through the whole process... They have a clear understanding what the service is providing and they access it.
> Interviewee

> ...some research is just benefitting the researchers... it's not benefitting the community (or) people who are struggling with health and struggling with things...It's not something that we've all decided on. It's just someone, 'All right, I've got this thing that...I'd like to focus on this area I'm working in. I want to do some research here,' but it mightn't be a priority within our communities... If it doesn't benefit our community and our work that we're doing, well we're wasting our time, and we won't waste people's time. We'll just say, go do it somewhere else.
> Interviewee

Underpinning this model are sustainable ACCHOs and the Aboriginal health workforce doing research and delivering healthcare across South Australia. ACCHOs and the Aboriginal health workforce form the foundation of healthy and thriving Aboriginal communities. Key research areas included: Aboriginal community capacity, empowerment, governance of Aboriginal community controlled health organisations (leadership, management and conflict resolution), opportunistic health screening and data collection. In addition is the need to develop strategic health policy and improve individuals' access to ACCHOs and culturally safe and flexible mainstream services. This would support the ACCHO sector and Aboriginal health workforce, especially in areas which do not have an ACCHO or where specialist, tertiary or specific health and wellbeing services are needed.

Recommendations

1. Aboriginal health should be considered in a holistic way and requires recognition of the interconnectedness of many factors in determining health or illness. Research into Aboriginal health and wellbeing needs to focus on the interconnectedness between cultural, spiritual, social and physical factors.

2. 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.

3. That ACCHOs are recognised as the central hubs for Aboriginal health and wellbeing. They advise about, collaborate with, and provide the essential links into Aboriginal communities, for the proper conduct of research.

4. That ACCHOs are funded accordingly in sustainable ways with a representative and gender-balanced Aboriginal health workforce, whose capacity to engage and conduct research is actively enhanced.

5. The role of the AHREC in approving, or otherwise, the conduct of research, requires adequate resources to monitor research activities and determine whether research proposals should be supported.

6. Priority areas for research into improving the health and wellbeing of Aboriginal people in SA should be reviewed by the ACCHO sector within five years' time.

7. The findings of this report are translated into user-friendly resources and are disseminated widely across the ACCHO sector, to universities, research institutes, SA Health, the National Health and Medical Research Council (NHMRC) and other relevant bodies.

(l-r) Ms Janet Stajic, Mr John Singer, Dr Rosie King, Ms Pat Anderson and Mr Romlie Mokak

AWARD

In March 2015, Next Steps was the inaugural recipient of the *Tarrn doon nonin* Award from the Lowitja Institute, Australia's National Institute for Aboriginal and Torres Strait Islander Health Research. This award recognises excellence in Aboriginal and Torres Strait Islander health research ethics.

REFERENCES

Aboriginal Health Council of South Australia, Indigenous Health Research Scoping Study, 2005.

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