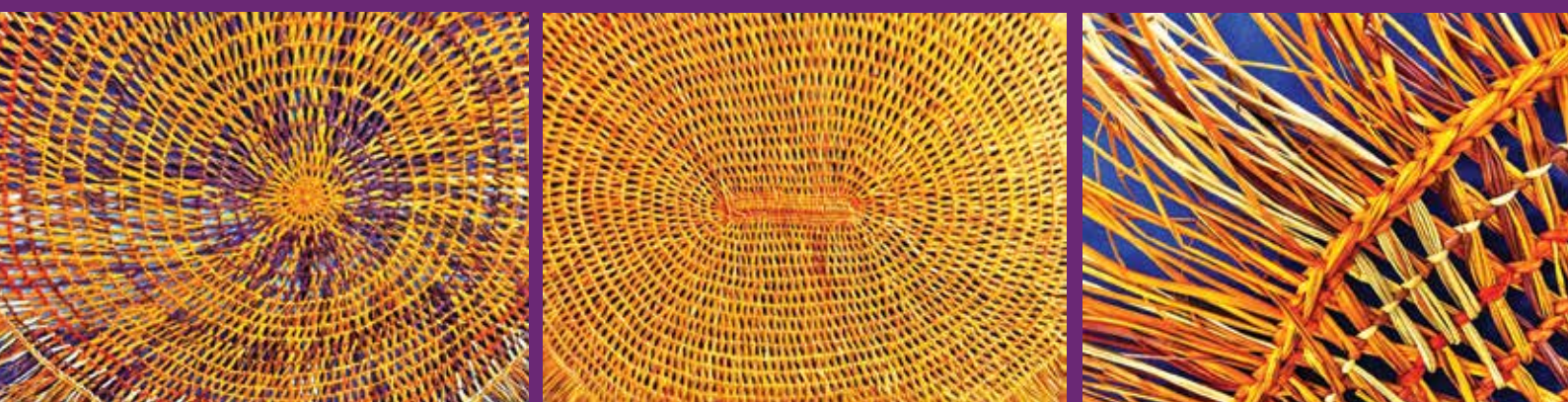


Next Steps for Aboriginal Health Research

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

Final Report
February 2015

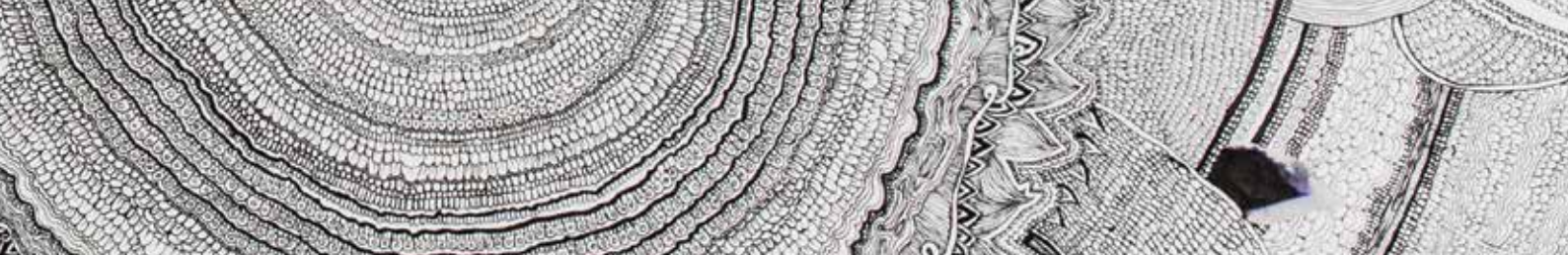


Cover Artwork – Anna Dowling, Ink on Paper, 2014

Aboriginal basket weaving (*Pictured Above*)

The patterns and shapes in the artwork are inspired by Aboriginal basket weaving, leaves, roots and other natural forms. The art of basket weaving shows the relationship and balance between Aboriginal people, their landscape and the natural world.

Thousands of fibres are connected together to form one strong body. The artist sees 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 in South Australia.



Contents

Next Steps for Aboriginal Health Research:
Exploring how research can improve the
health and wellbeing of Aboriginal people
in South Australia

Final Report – February 2015

Jointly prepared by:
Dr Rosie King and Professor Alex Brown

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



Next Steps awarded national recognition

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.



Foreword



Isabel Norvill (pictured left) is a Kurna – Ngarrindjerri woman from Murray Bridge. Emeritus Professor Ian Maddocks (below left) is an eminent palliative care specialist and a passionate advocate for world peace.

From 1986 both were members of South Australia's Aboriginal Health Research Ethics Committee (AHREC). While Ian stood down from the AHREC in 2011, Aunty Isabel has continued to provide thoughtful advice and pertinent, down-to-earth comment, like these responses to the Next Steps project report:

We're the most researched people.

The AHREC recognised research in Aboriginal communities as too often intrusive, paternalistic and ungoverned, an unhealthy combination. Sometimes it seemed designed more to satisfy academic research interests than to improve Aboriginal health.

The AHREC's 1989 guidelines for the better conduct of Aboriginal health research (AHCSA, 1989) helped the Ethics Committee of the National Health and Medical Research Council (NHMRC) to prepare its 1991 *Guidelines on ethical matters in Aboriginal and Torres Straits Islander research*, which were promoted as widely relevant (NHMRC, 1991; Maddocks, 1992).

There's a lot of stuff out there.

Aboriginal communities continue to face huge health issues that have largely resisted well-intentioned interventions. There are well conducted and ethical studies in progress, but more are needed.

It's not one for all. If you don't do the whole stuff, it's a drop in the ocean.

A holistic approach affirmed by Next Steps is essential. Each situation is different, but addressing a particular health problem, without examining it in the total context of

Aboriginal diversity, history and disadvantage, has limited value.

Without approval by the community, research is just lip service. You always have to contact the local people – all family groups need to be represented on Aboriginal advisory groups.

The community's own advice about what matters, and community ownership of measures devised to effect change, are crucial.

If you're going to do it, do it properly, eh?

Science must be rigorous, but Aboriginal Community Controlled Health Organisations (ACCHOs) need control over adequate intellectual and financial resources allocated for research.

It was Sorry Time, she broke the pencil and left the form untouched.

Sensitivity to the complexities of Aboriginal life is developed only by patient consultation and listening. Working through and with ACCHOs is essential.

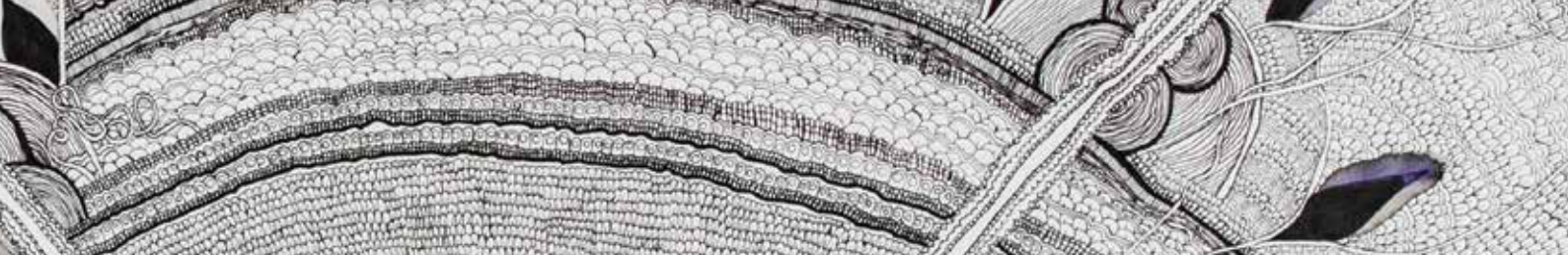
Sometimes you need to go back to go forward.

We learn best from mistakes. Regular review of research projects to see what has worked, and what has not, is a key recommendation of Next Steps.

Aunty Isabel and Ian both see the Next Steps initiative as directing research in Aboriginal health forward in ways necessary for effecting change.

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

**Aunty Isabel Norvill and
Emeritus Professor Ian Maddocks**



Acknowledgements

The Aboriginal Health Council of South Australia (AHCSA) undertook the Next Steps research project in partnership with the South Australian Health and Medical Research Institute (SAHMRI).

The Next Steps Research Team wishes to thank the Aboriginal Community Controlled Health Organisations (ACCHOs) and the Aboriginal Health Advisory Committees (AHACs) from across South Australia (SA) for supporting this study. In particular, our thanks and appreciation goes to each participant who gave their time to be interviewed and who participated in the Consensus Workshop. The value of your collective and individual input is immeasurable.

The Next Steps Research Team also acknowledges the seven-member Co-investigators' team for their significant and invaluable input into all aspects of this study. Indeed, their advice about issues impacting on health research in Aboriginal communities across South Australia has grounded the study in the realities of Aboriginal people's lives. The Next Steps Co-investigators were:

Mr John Singer, Executive Officer
Nganampa Health Council

Ms Belinda Hammond, Research Officer
Nunkuwarrin Yunti of South Australia Inc.

Ms Karen Glover, Chief Executive Officer
Pangula Mannamurna Aboriginal Community Controlled Health Service

Mr Mark Thompson, Coordinator
Aboriginal Clinical Services, Drug and Alcohol Services of South Australia

Dr David Scrimgeour, Public Health Medical Officer
Aboriginal Health Council South Australia Inc.

Dr Merridy Malin, Rising Spirits Research Coordinator
Aboriginal Health Council South Australia Inc.

Dr Nick Williams, GP Supervisor
Aboriginal Health Council South Australia Inc.

For her work on the literature review and assistance with interviews during a Social Work placement from Flinders University, we thank Claire Deves. We are grateful to Ms Kim O'Donnell for her enthusiastic and engaging facilitation of the Consensus Workshop.

SAHMRI also provided staff from the Wardliparingga Aboriginal Research Unit to assist with research training and support. In particular, Ms Kathy Mott, Dr Carol Davy, Ms Anna Dowling, Mr John Gray and Ms Tania Marin are acknowledged and appreciated for providing their hands-on support and expertise throughout this study.

With thanks from the Next Steps Research Team:

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Aboriginal Health Council South Australia Inc.

Ms Janet Stajic, Next Steps Research Officer
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Professor Alex Brown

Wardliparingga Aboriginal Research Unit, SAHMRI; and

Ms Kim Morey, Manager

Knowledge Translation and Exchange, Wardliparingga Aboriginal Research Unit, SAHMRI



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



Executive Summary

Background

The Next Steps project first began in 2011, having evolved from several pieces of work undertaken previously at the Aboriginal Health Council of South Australia (AHCSA), together with the work of the Aboriginal Health Research Ethics Committee (AHREC).

The establishment of SAHMRI and the Wardliparingga Aboriginal Research Unit provided an opportunity to conduct a comprehensive review of community priorities for research. Mutually agreeable study methods were devised and in 2013, Next Steps became the first project undertaken in partnership by AHCSA and SAHMRI.

Study Methods

The table below provides an outline of the study methods and the timeframe in which the different components of this study were carried out:

Phase One: November 2012 to December 2013

Literature review

Preliminary audit of AHREC database

Ethics application granted (Nov 2012)

Consultancy Agreements signed between AHCSA and SAHMRI – Feb 2013 and Jan 2014

Next Steps Research Officer commenced May 2013

Engagement with Co-investigators, ACCHOs and AHACs throughout project

Interviews with ACCHOs and AHACs commenced Nov 2012 and were completed Dec 2013 (N=59)

Phase Two: January 2014 to May 2014

Interview data analysis

Co-investigators' training and data analysis

Ethics modification granted

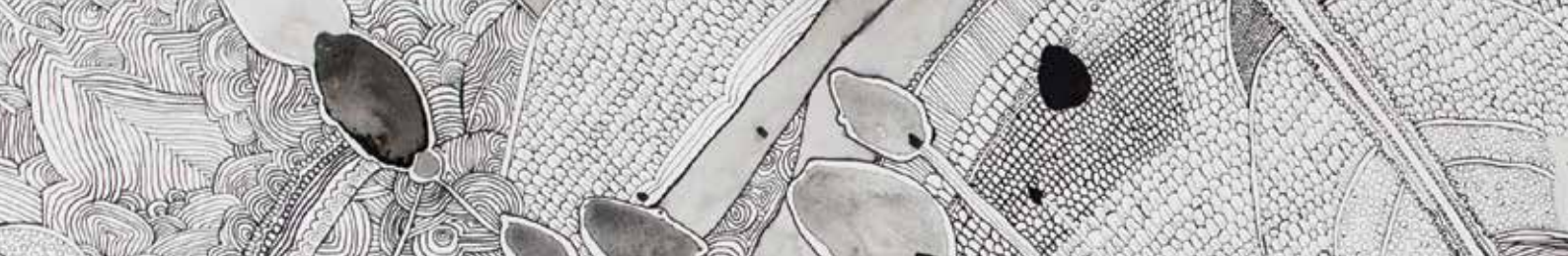
Second audit AHREC database (March 2014)

Consensus Workshop (April 2014)

Aim of the Next Steps Project

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 (ACCHOs), Aboriginal Health Advisory Councils (AHACs)¹ and the Aboriginal community in South Australia (SA).

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.



Executive Summary

Key Findings

A summary of the key findings of interest is presented as a model which captures the five main health and medical research priority areas identified during the course of this study.

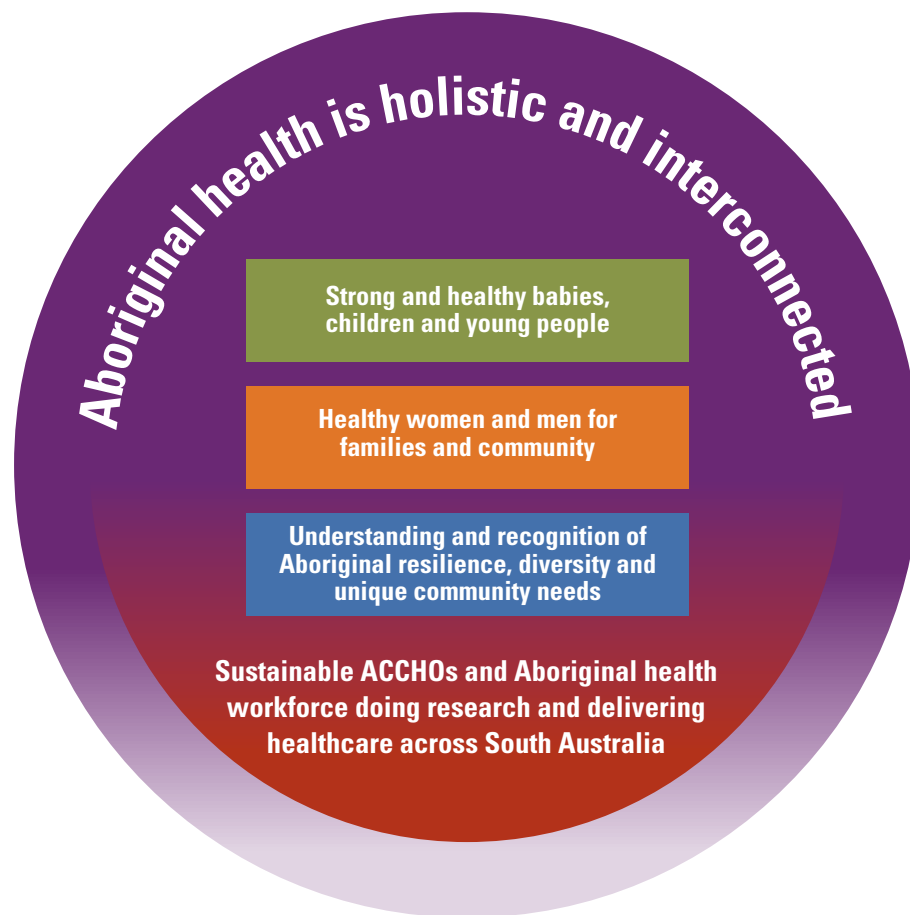


Figure 1: Model of five main health and medical research priority areas



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, for example 'cancer' or 'grief and loss', need to be explored within real life contexts which consider a range of contributing factors such as employment, racism and social networks.

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, the social and emotional wellbeing of mothers, and the role of fathers in child caring and rearing.

A critical area of research is the need to know more about the disproportionate levels of suicide amongst young Aboriginal people, identification of critical intervention opportunities and the composition of culturally appropriate support services.

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 into which more research is needed. Research is needed to help support and grow a male Aboriginal health workforce for employment in the health sector and within ACCHOs 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

A major priority area was the need to understand and strengthen resilience, diversity and unique community needs in Aboriginal communities. A number of specific health conditions were singled out as being of unique concern because of their prevalence, coupled with inadequate, inappropriate or delayed treatment. Some communities were



Executive Summary

overwhelmed by the impact of health conditions and this was thought to have an undesirable effect on both individual and community resilience. Health conditions of most concern were diabetes; cancer; cardiovascular disease; asthma; obesity in both adults and children; childhood illnesses including the early onset of chronic disease; blood borne viruses; co-morbidities and multi-morbidities and human immunodeficiency virus (HIV).

Each Aboriginal community has a unique set of needs depending on history and location. These factors contribute to substantial differences between communities, particularly in relation to 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. It's about, I suppose, when you develop things. 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

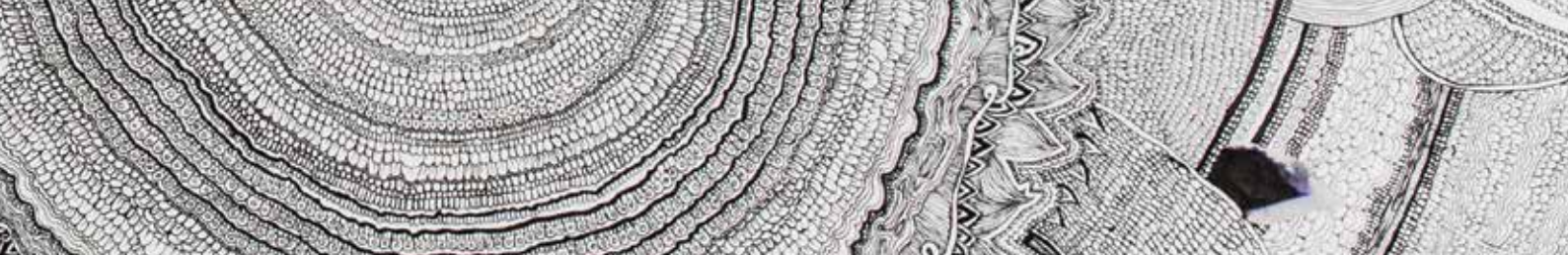
...research has to be able to steer governments into the right direction....some research is just benefitting the researchers...it's not benefitting the community (or) people who are struggling with health and struggling with things...It's not something that we've all decided on. It's just someone, 'All 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, what they're doing. Sometimes that's where it gets mixed up... They might be only able to get money that focuses on certain projects so that's the way they go, but if it's not (our priority) well I'm not worrying about research that someone is bringing in for themselves. 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 are understood to form the foundation of healthy and thriving Aboriginal communities.

The key areas for research within this sector included Aboriginal community capacity, empowerment, governance of Aboriginal community controlled health organisations (leadership, management and conflict resolution), opportunistic health screening and data collection.

Finding ways to develop strategic health policy and improve individual's access to culturally safe and flexible mainstream services 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.

Lastly, a significant outcome of this study pointed to the need to strengthen translation of research findings into policy and practice in very tangible ways.



Recommendations

Recommendations for researchers

- To respect the authority of ACCHOs and to do their homework on the organisation, Aboriginal population and local area.
- Find out about cultural protocols and follow them.
- Seek guidance from an Aboriginal cultural mentor.
- Be prepared to drop their own (or industry) agenda(s) and consult with Aboriginal people to find a topic of benefit to Aboriginal people which is relevant to community needs and therefore more likely to produce a tangible outcome.
- Seek advice on the most appropriate way of recruiting participants.
- Submit all research proposals for ethical review by the AHREC.
- Work in partnership with Aboriginal people to empower them and build their research capacity.
- Minimise or make every effort to reduce the burden of research on an ACCHO and on individuals.
- Be informed about the circumstances of ACCHOs and have realistic expectations, especially if the research is located in remote areas.
- Use appropriate communication and correspondence methods and not use academic language.
- Exercise common courtesy by respectfully asking questions, rather than being demanding, self-interested or unpleasant.
- Tread extra carefully if the research concerns sensitive issues or is likely to occur at crucial time of life.
- Provide honest feedback on the findings and organise networking events aimed at sharing knowledge with the Aboriginal community, participants and with ACCHOs. Acknowledge everyone's input.

General recommendations

- 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.
- 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.
- That ACCHOs are recognised as the central hubs for Aboriginal health and wellbeing, who advise about, collaborate with, and provide the essential links into Aboriginal communities for the proper conduct of research.
- 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.
- 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.
- Priority areas for research into improving the health and wellbeing of Aboriginal people in South Australia should be reviewed by the ACCHO sector within 5 years' time.
- The findings of this report are translated into user-friendly resources and are disseminated widely across the ACCHO sector, to universities, research institutes, the SA Health, the National Health and Medical Research Council (NHMRC) and other relevant bodies.



Context of Research

Context of research involving Aboriginal people

Beginning in 2011, the origins of Next Steps for Aboriginal Health Research: Exploring how research can improve the health and wellbeing of Aboriginal people in South Australia (called Next Steps) can be traced back to May 1986, when the Aboriginal Health Research Ethics Committee (AHREC) became the first Aboriginal Human Research Ethics Committee in Australia². While Next Steps is understood to have evolved from more recent work undertaken at the Aboriginal Health Council of South Australia (AHCSA), its foundations lie in the concerns of the inaugural AHREC members to take control of the way in which research is done and because of:

...concerns about previous research going unchecked in Aboriginal communities.
(Aboriginal Health Council of South Australia, 'AHREC Inaugural Bulletin', November 1989).

In Australia today, the health and wellbeing of Aboriginal people must be understood within a context of dispossession of culture and land, relatively newly introduced illnesses and racism, which have led to poverty and exclusion from many types of healthcare. As social movements and new levels of activism arose in the 1960s, calls for improved health standards were linked to empowerment (Carson et al, 2007). In 1971, the first Aboriginal medical service utilising a primary healthcare approach was established (in Redfern, Sydney). Soon to be followed by the development of other ACCHOs around the country, the primary healthcare approach was considered:

...innovative and mirrored international aspirations at the time for accessible, effective, appropriate, needs-based healthcare with a prevention and social justice focus.(National Aboriginal Community Controlled Health Organisation (NACCHO) History, <http://www.naccho.org.au/about-us/naccho-history/#intro> Accessed 14.08.2014)

From these developments, it is noted that ACCHOs became key strategic sites for Aboriginal community development. However, while there has been progress and development in many areas, the field of health research has lagged behind. Regular observations of the AHREC

were how few research projects properly engaged with, or were initiated by Aboriginal people or the ACCHO sector (refer to Appendix 1, Map of the South Australia ACCHOs and AHACs).

According to the National Health and Medical Research Council (NHMRC), proper ethical review includes questions about the research merit and integrity, the risks and benefits (or beneficence) of research, consent (or respect), and fair recruitment (or justice) of research. But there were too many instances where the main benefit from research did not rest with the community, nor were the outcomes necessarily benefits the community themselves would have liked to see. Such frustrations from AHREC members and the ACCHO sector raised the following questions:

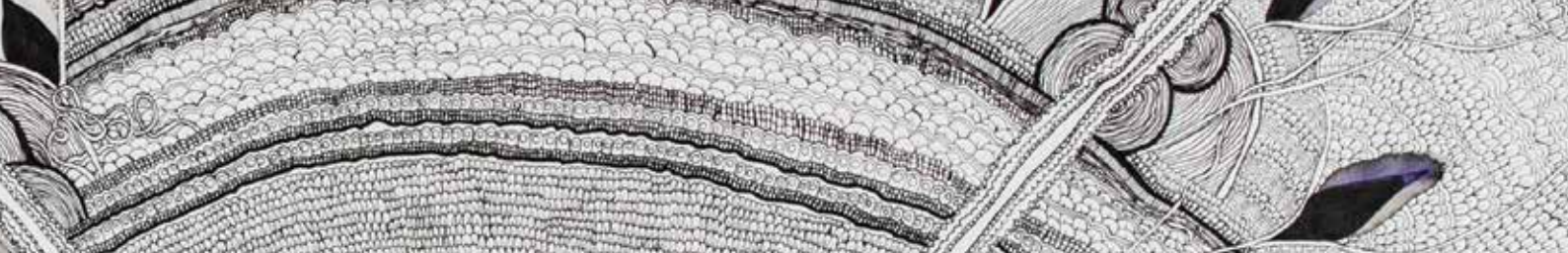
- Why were so many Aboriginal people disenchanted, disengaged and disempowered by the research process?
- Was research focussing on the topics that were of most concern to Aboriginal people?
- How should research be conducted to engage Aboriginal communities and more appropriately meet their health needs?

AHCSA had previously been part of a Centre of Clinical Research Excellence (CCRE) in Aboriginal and Torres Strait Islander Health from 2003 to 2008, with Flinders University of South Australia. Formed as a collaborative project in chronic condition research, it was the first CCRE to focus on Aboriginal health research and involved AHCSA, several ACCHOs and various researchers. The CCRE was established to:

...conduct high-quality Aboriginal-controlled health research in Aboriginal communities, focusing on the prevention and management of chronic and complex conditions. (CCRE, CCRE Achievements and Milestones, 2008: p2.)

During its operation, the CCRE developed a number of initiatives in research, research education and program translation (Centre of Clinical Research Excellence in Aboriginal and Torres Strait Islander Health 'CCRE Achievements and Milestones', 2008).

² For further information on the AHREC, refer to 'Additional Resources' in this report



Most notably, the CCRE:

- Established several research programmes within the communities of CCRE partner organisations, focussing on managing and preventing chronic and complex health conditions such as diabetes and cardiovascular disease;
- Created materials for and delivered the Certificate IV in Indigenous Research Capacity Building, in collaboration with James Cook University and located at AHCSA, as well as funding scholarships for Aboriginal students to prepare for and complete university studies;
- Produced a range of culturally relevant and informative materials; and
- Linked the ACCHO workforce with relevant training programmes such as emergency mental health, alcohol and other drugs and safe medication management.

While the CCRE was conceived and designed to build research capacity within AHCSA, there were many challenges. A key learning was the need to ensure Aboriginal community-controlled organisations are able to administer their own research grants. This led to a call for:

An independent and authoritative research program run by Aboriginal communities... supported through (AHCSA) and guided by AHREC... to ensure that research produces programmes and strategies that can ultimately lead to improved health status for Aboriginal people. (CCRE, CCRE Achievements and Milestones, 2008: p6.)

In 2005, the AHCSA commissioned the Indigenous Health Research Scoping Study (Aboriginal Health Council of South Australia, Indigenous Health Research Scoping Study, 2005), to report on issues related to Aboriginal health research in South Australia. The Indigenous Health Research Scoping Study (IHRSS) was the first Aboriginal health research initiative involving AHCSA working in collaboration with the South Australian Department

of Health, Flinders University of South Australia, the University of Adelaide and the University of South Australia.

The IHRSS aimed to establish some clear priority areas that would assist in making informed decisions about where to focus research efforts and research funding, and to identify research capacity in South Australia to work on particular priority areas. From this study, a foundation was laid for consideration of a more strategic and coordinated approach to planning, designing, conducting, managing and monitoring research. It articulated the need for knowledge gained through research to be translated into policy, programs and practices that made a real difference to the health and wellbeing of Aboriginal⁹ people and their respective communities, as well as to the delivery of health services to Aboriginal people.

Two primary recommendations came out of the IHRSS. Firstly, this study identified the need for the development a South Australian Aboriginal Health Research Coordination Centre based outside of the university sector. Secondly, for research that involves Aboriginal people to have a much greater focus on action and intervention.

Since its publication in 2005, some activity has been undertaken which either directly or indirectly addressed issues identified by the IHRSS. However, the main recommendations have not been implemented, nor has any systematic approach been taken to determine the research priorities for Aboriginal people living in South Australia.

In August 2011, the AHCSA Full Council of Members endorsed an audit of AHREC approved research activities (January 2006 to December 2011), as well as surveying ACCHOs and AHACs about the conduct of research and research topics. In mid-2012, the collaboration between AHCSA and SAHMRI was formed to identify South Australia Aboriginal health research priorities. Next Steps became the first project undertaken in partnership by AHCSA and SAHMRI's Wardliparingga Aboriginal Research Unit.

⁹ According to the IHRSS (2005), the 'wider factors impacting on health' included housing, homelessness, education, employment, occupational health and safety, environmental health, race and race relations, reconciliation, language reclamation, land and identity, social determinants of health, and transport. 'Social emotional wellbeing matters' included child protection and abuse, young people in care, family support, family violence, substance misuse, drug diversion, social-emotional wellbeing, mental health, youth, juvenile justice and crime prevention.



Context of Research

Context of research involving Aboriginal people

One of the main motivations for Next Steps concerned reclaiming the research agenda back from research topics defined by the research sector (that is, Universities and State or Australian Government) to topics of concern and of direct benefit to the Aboriginal community. Aboriginal health research needs to be driven by the experience of Aboriginal people at the coalface of health service delivery and by South Australian Aboriginal communities who are living with health issues on a daily basis.

Aim

The aim of the Next Steps research project was to identify and prioritise the main public health research areas that align with the needs and interests of Aboriginal people within the Aboriginal Community Controlled Health Organisations (ACCHOs), Aboriginal Health Advisory Councils (AHACs) and the Aboriginal community in South Australia.

We also wanted to find out:

- What were the main topics of health research involving Aboriginal people in recent years?
- Is there a difference between the health research topics undertaken by researchers and the topics considered important to the South Australian Aboriginal community?
- How should research involving Aboriginal people be conducted?

What benefits would Next Steps provide to Aboriginal people and to the ACCHO sector?

The development of Aboriginal-driven research priorities would help re-focus research on health issues that affect South Australian Aboriginal communities. ACCHOs are frequently asked to provide support for research that is primarily defined by non-Aboriginal researchers, where they are often passive participants, not partners. As the AHCSA is the peak body and the 'health voice' representing Aboriginal people in South Australia, a more informed understanding was needed about what research would benefit Aboriginal communities and more effectively meet their needs.

With this knowledge, the AHCSA can be empowered to advocate for preferred areas of research and inform researchers about topics which will potentially provide more benefit to Aboriginal people in South Australia. Furthermore, as the AHREC has specific objectives (Appendix 2) and operates as an independent sub-committee of the AHCSA, research priorities generated by Aboriginal people in South Australia will assist with both the ethical deliberations of the AHREC and with offering guidance to and advising researchers on how to conduct research and preferred topics likely to yield the most benefit to the health and wellbeing of Aboriginal people.



Our Approach

Our approach to Next Steps

Collaboration and Engagement

At the core of this study is the engagement with, and participation of, staff who work in Aboriginal Community Controlled Health Organisations (ACCHOs). An Aboriginal Research Officer was employed to coordinate the project and work with all AHCSA members to ensure the process was open, inclusive and worked effectively. Co-investigators were invited from ACCHOs and within AHCSA staff.

The input and perspectives of the AHACs and ACCHOs were fundamental to this study, forming a crucial link with Aboriginal communities and in formulating an Aboriginal-centred knowledge base for the development of research priorities and for informing approaches to the proper conduct of research with and for Aboriginal people.

The engagement process involved contacting each of the Chief Executive Officers (CEOs) of the ACCHOs and the AHAC Chairpersons to explain the details of the project and to seek their support to be involved in the project. A support letter template was provided to each of the organisations as well as a 'key contacts' sheet for CEOs and Chairpersons to identify possible participants. Following this initial process of engagement, the Next Steps Research Officer followed up every site by contacting each staff, Board or AHAC member to arrange a suitable time and location for interviews to occur. We found that most people interviewed felt being involved in the project was worthwhile and of benefit to their community.

Study Methods

The description below provides an outline of the study methods and the timeframe in which the two phases of this study were carried out.

Phase one: November 2012 to December 2013

In 2012, a literature review was undertaken to ensure the need for this project. Ethics approval was granted in November 2012 by the AHREC and the engagement with the ACCHOs and AHACs began. In December 2012, the Co-investigators' Group was formed to steer the project and advise

the Next Steps investigators throughout the project on participant recruitment, data collection, data analysis and dissemination of the results and promote the aims and objectives of the project. The Co-investigators' Group also offered advice on issues impacting upon health and wellbeing research in Aboriginal communities in South Australia. The 'Terms of Reference' document for the Co-investigators' Group is attached in Appendix 3. The Co-investigators met seven times between December 2012 and March 2014. They also attended the Consensus Workshop and provided input into this report.

A confidential database of all research proposals reviewed by the AHREC since January 2002 is maintained at AHCSA. The aim of the audit of the AHREC database was to determine the focus of the research topic, the geographical location of where the research was conducted, the types of research methods used and who (what organisations/institutes) conducted the research. An initial audit of approved research proposals dated from January 2003 to September 2012 (N=341) was undertaken in 2013. However, as there were missing data, a second more detailed audit of reliable data within the database was undertaken and completed in March 2014. SAHMRI staff assisted with this task and all those involved signed an AHCSA confidentiality agreement.

A Microsoft Access database was developed to collect the data from the audit which was firstly populated with data from the existing AHREC Microsoft Access database and the remaining data was added manually from hard copies of the AHREC files. This audit included a total of 212 approved research proposals submitted to AHREC from February 2010 to February 2014.

A purposive sample was invited from staff and boards of each ACCHO in South Australia, Chairpersons and members of all AHACs and a number of other Aboriginal organisations or key informants considered as being important in this process. All participants were aged 18 years and over.



Our Approach to Next Steps

Formal consent to participate in face-to-face interviews was obtained from each of the participants. Each person identified on a key contacts sheet was contacted, assured their involvement was voluntary and interviews would be kept confidential. Arrangements were then made to conduct the interview at a suitable time and place for both the participant and the ACCHO or AHAC. Where face-to-face interviews were not possible, arrangements were made for a telephone interview. The interviews lasted between 40 minutes to an hour.

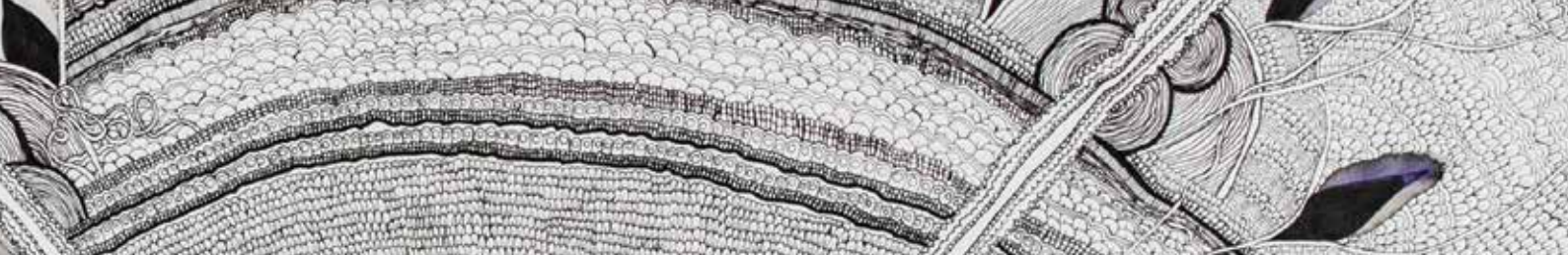
A semi-structured interview schedule was developed in which demographic data was collected as well as opinions about the most concerning health issues, perceived gaps in knowledge and gaps in strategies and services to address health needs/issues, and participant's thoughts about how research may assist in addressing some of the issues they faced as health service providers, advisory group members or Aboriginal advocates and community representatives. Participants were also asked to offer their opinion on the current and future conduct of Aboriginal research in South Australia.

As this study concerned developing research priorities, it was considered to pose minimal risk to participants. The researchers recognised that participants' workplaces were often busy and demanding environments and made every effort to minimise disruption and reduce any burden on participants or their workplace. However, the researchers were conscious that there were potential social and/or emotional risks, particularly if the conduct of research was not a smooth or well-supported process or there had been workplace concerns, such as cultural safety for Aboriginal staff or differences between management and staff experiences and views. Protocols were developed to address cultural safety issues, the risk that participants could be identified and participants' right to withdraw, as well as access to personal support. While the names of individuals are confidential, the names of the ACCHOs, AHACs and substance misuse services who participated are in Appendix 4.

Audio recording of interviews was undertaken where consent was provided. Hand written notes were made when participants did not consent to audio-recording. All interview materials were transcribed by an external transcribing service and imported to NVivo data analysis software for coding and analysis. Interpretation of the data was undertaken by the research team members and the Co-investigators' Group. A total of 59 interviews were completed between November 2012 and December 2013.

Phase two: January 2014 to April 2014

The second phase of the project commenced in early 2014, when a more detailed audit of the AHREC database was completed in March. This audit included a total of 212 approved research proposals, dated from February 2010 to February 2014. Framework analysis was used for analysing and interpreting the interviews to effectively manage the large amount of qualitative information generated by the semi-structured interviews. In the first instance, Co-investigators met and agreed upon a high-level framework which comprised of the four primary research questions. Utilising a qualitative software package (NVivo v10), research staff then read the interview transcripts, systematically attributing relevant text from each interview to the relevant primary research question (coding). Co-investigators were then provided with a printout of the information from all interviews that related to each question. Through a series of facilitated workshops, Co-investigators were supported to analyse and interpret the findings, addressing each of the primary research questions in turn. The preliminary findings were drafted and a Briefing Paper developed and provided to participants of the Consensus Workshop held on 1 and 2 April 2014.



Results

Key Results

Aboriginal health is holistic and interconnected

The strong conviction that health cannot be seen in isolation was highlighted throughout this project. Consequently, research into Aboriginal health and wellbeing needs to focus on the interconnectedness between cultural, spiritual, social and physical factors. This is a foundational priority. Research topics that are of particular interest, for example 'cancer' or 'grief and loss', need to be explored within real life contexts, which consider a range of contributing factors such as employment, racism, social networks etcetera.

These findings support Watson's et. al (2010) definition of the social determinants of health, which includes housing, education, employment, social networks, connection with land, racism and law enforcement (Watson et. al, 2010: 6). Conducted in 2005, findings from the IHRSS⁴ audit indicated a total of 54.2% of studies focussed on 'wider factors impacting on health' (29.2%) and 'social and emotional wellbeing matters' (25%).

While several studies in the Next Steps audit (conducted in 2014) focussed on the over-arching social determinants of health (9%); and four studies focussed on 'general health and culture', it was difficult to determine whether or not they represented a holistic or connected approach to all aspects of the social determinants of health for Aboriginal people in South Australia.

Strong and healthy Aboriginal babies, children and young people

The interviews highlighted the need to prioritise research that focused on Aboriginal babies and children (from pregnant mother's antenatal care to when the child is 14 years) and ensuring that young people (aged 15 to 24 years) were supported to grow up strong and healthy. Only two studies (less than 1%) focussed on this theme during the audit

period (2010 -2014). Prior to 2005 there were examples of research related to early development and children's health. As was highlighted throughout consultations, a greater understanding of the factors that contribute to thriving infants and children (up to 3 years' of age) is needed.

Priority areas included foetal alcohol syndrome, nutrition, antenatal care – particularly in relation to women smoking tobacco and drinking alcohol whilst pregnant – maternal health, the social and emotional wellbeing of mothers and the underexplored area of the important role of fathers in child caring and rearing. Importantly, the proportion of children and young Aboriginal people in the South Australia population has steadily increased indicating a relatively young and quite different age structure compared with the non-Aboriginal population (ABS, 2009).

Research into the disproportionate levels of suicide among young Aboriginal people, identification of critical intervention opportunities and culturally appropriate support services was considered a key but as yet underexplored research priority.

Healthy Aboriginal women and men for families and community

Women as mothers and carers of children, and the general health of men featured as two specific topics within a number of themes identified within the interviews. None of the studies in the audit focused on women in their parenting role; however, there were three studies (1.4%) that focussed specifically on Aboriginal men's health. In the Consensus Workshop, there was strong discussion of the need for more Aboriginal male health workers to be employed in health to provide culturally appropriate services, greater gender balance and to contribute to better health outcomes for Aboriginal men. There is also the opportunity to utilise research to help support and grow a male health workforce within ACCHOs.

⁴ According to the IHRSS (2005), the 'wider factors impacting on health' included housing, homelessness, education, employment, occupational health and safety, environmental health, race and race relations, reconciliation, language reclamation, land and identity, social determinants of health, and transport. 'Social emotional wellbeing matters' included child protection and abuse, young people in care, family support, family violence, substance misuse, drug diversion, social-emotional wellbeing, mental health, youth, juvenile justice and crime prevention.



Results

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

Research is needed to understand what defines and contributes to Aboriginal people's resilience in the face of ongoing health and social disadvantage. This is a critical stepping stone to strengthening communities to build better futures for Aboriginal people. In the audit of recent research projects, 6.6% of studies focussed on social and emotional wellbeing and 2% on mental health issues.

Despite a strong sense from community informants of the existence of many locally defined solutions to mental health and social and emotional wellbeing issues, communities felt that they were rarely heard or empowered through research or policy to create or define their own way forward. Research, as a minimum, must support empowerment of communities and services. Impacts of colonisation were cited as causing long term disadvantage for Aboriginal people particularly in terms of health and wellbeing. However, the empowering role of education was valued as an enabler to improve Aboriginal people's health and well being, as well as their standard of living.

Diversity and inequalities between Aboriginal and non-Aboriginal people, between communities and across different geographical locations were consistent themes in the data.

Challenges particular to remote areas included the availability of clean water, general hygiene, poverty, and inadequate housing and language barriers. In rural and remote communities, concerns over the availability and affordability of food persist, as does the relationship between food availability, food choices and chronic diseases. The nexus of food and chronic disease was identified as a priority question for future research. Broader issues of the differences between services and communities included aspects of funding, incorporating operational funding, and the differences between urban, rural and remote funding levels.

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

Consultation findings highlighted that it remains imperative for research efforts to prioritise the development and implementation of sustainable interventions that support or deliver tangible improvements to the health and wellbeing of Aboriginal people. There is little doubt that all research efforts need to include a focus and investment in Aboriginal capacity building. The two key priority areas for action proposed by the IHRSS (2005) included the establishment of a state-level Aboriginal health research coordination centre and an increased focus on research with an action and intervention orientation. These findings were corroborated by the findings in this study.

A fifth of studies in the audit focused on 'health services research', including those undertaken in a hospital setting. However, consultations highlighted a strong sense from the sector that ACCHOs need their own dedicated research funding to undertake studies on issues of importance to the sector itself, including:

- Governance: the mechanisms, processes and relations by which both corporate and community governance operates to control and direct Aboriginal health services, advisory bodies and community members;
- Health sector and inter-sectoral accountability, particularly in relation to responsibility for providing and delivering equitable, effective and accessible healthcare services to Aboriginal people and greater input and control by Aboriginal people into health program development and delivery;
- ACCHO health service accessibility across South Australia for all Aboriginal people;
- Provision of high quality healthcare to Aboriginal people which has culturally appropriate and effective models of care based on interconnected and holistic understandings of health and well being;



- Sustainable funding models for Aboriginal Health Workers, ACCHO services and programs;
- Program monitoring, evaluation and inter-sectoral collaboration on knowledge translation; and
- Aboriginal workforce development with a priority on attracting young Aboriginal people to work either in the ACCHO sector or broader health sector, increasing the number of male Aboriginal health workers, Aboriginal registered nurses and other Aboriginal health workforce personnel.

Audit of the Aboriginal Health Research Ethics Committee database

A detailed audit of the AHREC database was completed in March 2014. This audit included a total of 212 files of approved research proposals dated from February 2010 to February 2014. Refer to Appendix 5 for additional detail on the findings of the audit. The findings presented here will focus on the primary focus of the research; the location of the research; the extent of research undertaken with an ACCHO; the participants in the research; the levels of governance indicated, consultation and Aboriginal capacity building.

What was the primary focus of the research?

Among the wide range of health topics covered by proposals, over half (52%) of the 212 studies were focused on health services research (22% or 47 studies), general health (11% or 23 studies), chronic disease (10% or 22 studies) and social determinants of health (9% or 19 studies). The remaining 48% of research topics was spread among nine different topics areas, including alcohol and other drugs (N=18), social and emotional wellbeing (N=14), health promotion (N=13), health prevention (N=11), population health survey (N=10), nutrition (N=8) and other (N=15). Notably, mental health and obstetrics and gynaecology had the fewest number of studies, at 3% or six studies each.

Where was the research located?

Of the 212 research projects, 52 were national projects, 87 were located across South Australia and 73 involved discrete parts of South Australia. Forty eight percent of the studies were located in metropolitan Adelaide, 22% in the northern region of South Australia, 15% were in the Eyre region. A total of two studies were conducted in Mount Gambier. Importantly, no studies undertaken during this four-year period were solely located in the Riverland; however, this area may have been included in projects involving the whole of South Australia or national projects.

How much research was undertaken within an ACCHO?

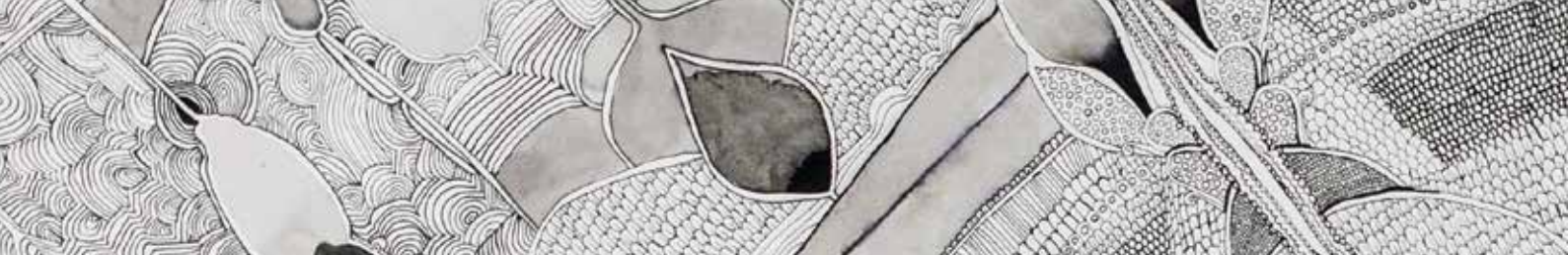
Fourteen percent of studies were conducted within an ACCHO.

Who were the participants in the research?

Almost 63% (N=133) of studies stated the participants were Aboriginal and Torres Strait Islander. Studies involving the general Australian population formed 41% (N=88), whereas 24% (N=52) of studies included health providers, such as clinicians, managers, administrators or ancillary staff.

What was the level of governance indicated in the research?

Governance structures were defined by how and to what extent the study was managed, conducted and controlled by Aboriginal people, as indicated in the proposal application form. This included determining if the research was totally controlled by Aboriginal people (that is, 100% governance); a majority of Aboriginal people; there was an Aboriginal Chief Investigator; and the proportion of Aboriginal people involved in an advisory structure which could range from 100% Aboriginal representation to none at all. Providing advice can include giving guidance on cultural matters or methodology. However, it is important to note that while advice may have been indicated in the governance structures, it was beyond the scope of the



Results

audit to determine to what extent advice was actually followed.

The audit indicated Aboriginal people's involvement in the governance of research projects was most strongly represented in advisory structures (36%), whereas levels of Aboriginal governance were more of a rarity at 7%. Indeed, 42% (N=89) of research projects had no Aboriginal people involved in the overall management or advisory structure. This figure includes projects conducted on the general population, which included Aboriginal and Torres Strait Islander people. Questions about research governance were not asked in proposal application forms as they were not considered part of ethical review processes.

How much consultation was undertaken in the research?

While 50% of researchers consulted with Aboriginal communities and services, there were 48% that indicated consultation as being 'once only' or 'none'. It is worth noting that in recent years it is far less likely that AHREC approval would be provided if minimal or no consultation occurred.

What indication of Aboriginal capacity building was in the research proposal?

From 2011, a new AHREC proposal form was introduced which included questions about consideration of Aboriginal capacity building in research. Over this period nearly one third (29%) of studies considered or included varying components of Aboriginal capacity building. However, the results of this audit do not exclude general population studies looking at historical medical records in a hospital setting. Notwithstanding this, 69% (N=147) of studies indicating no Aboriginal capacity building remains a disappointing figure in this context.

Interviews with Aboriginal Health Advisory Committees and Aboriginal Community Controlled Health Organisations

The qualitative component of the Next Steps study identified six overarching findings and 10 primary themes which were of concern to participants. Under each primary theme are suggestions of topics for research to focus on in the future.

Participants were also asked a number of questions about the conduct of research. The main findings from these questions are presented towards the end of this section.

Overarching findings

- There was a very clear emphasis on babies, children and young people throughout the interviews. 'Growing up strong and healthy' was a focus of all the themes.
- Women in their parenting role and men in terms of their general health featured as two other specific population groups identified within a number of themes.
- Health cannot be seen in isolation. Participants focused on the interconnectedness between cultural, spiritual, social and physical factors.
- Aboriginal communities were described as resilient and participants believed that research needs to support and build upon this strength.
- There were noticeable inter-regional differences in the data, particularly between urban, rural and remote regions.
- In many instances, research has already identified the issues which would improve the health and wellbeing of Aboriginal people. What is now required is the development and implementation of sustainable interventions for tangible improvements to the health and wellbeing of Aboriginal people.



Theme one: Social and emotional wellbeing and mental health

Issues identified by participants within this theme included grief, loss, stress and trauma:

I believe there are enormous grief and loss issues associated... with ongoing issues and dispossession. Interviewee

...when we speak about social/emotional wellbeing, we're looking at the effects of past policy, of history in general, we're looking at the absence of family, with little to no connection with the country, and – yeah. So not knowing who you are is probably one of the major things I'd put there. Because if you don't know who you are, a lot of the times it's like a domino effect, and all those other things can come into play. You have to deal with the underlying causes and – otherwise you're putting a Band-Aid over the top. Interviewee

Grief, loss, stress and trauma were often experienced in parallel and when combined, significantly impacted on Aboriginal and Torres Strait Islander people's wellbeing. These issues were believed to be associated with both physical and mental illnesses including depression:

I suppose the biggest impacts I see are issues surrounding grief and loss, and the consequences of that. So impacts on health not only physically but mentally as well, and impact on the larger family unit and impact on community... (and) that links in with diabetes, cardiovascular disease... I know that's not the be all and end all, but... that constant grief and loss that's been passed on from generation to generation... We're dealing with generations of issues. Interviewee

If you have a really bad month you have a community that just is grieving. If you have half a dozen funerals in a month then people come home. All we're doing is preparing every week for a funeral, or maybe twice that week. I can remember a few years

back when there was 30 funerals in this community (over four months) so... that sort of compounded grief, how do people manage that? ...I guess I'm also aware that a lot of those issues... (have) background factors... it's often the inter-generational grief and loss. It may not be this particular generation of young people, but they may have parents, grandparents (etc.) who to this day are suffering from that grief and loss and that has in turn impacted on their life chances. Interviewee

A lack of hope, particularly for young people, and constant worry that never appears to subside were believed to further diminish people's ability to cope with other issues encapsulated within this theme.

A need for more services that support the social and emotional wellbeing of all Aboriginal people, but in particular those suited to young people and children, was identified. In addition, clarity about the most effective models of care to support social and emotional wellbeing was also required. In particular, this related to how care should be provided and who might be best placed to provide that care. Finally, participants believed that research could assist the community to better understand how historical trauma impacts upon, and plays out within families and communities.

Inter-regional differences

Social, emotional and wellbeing issues, including the impact of historical trauma, were pervasive across all settings. There were, however, contextual differences relating to the availability of appropriate services to deal with these issues. Urban participants were concerned about the provision of culturally appropriate mental healthcare. They suggested that although services may be available in the city, these were mainstream services and may be neither effective for, nor acceptable to, Aboriginal people. In comparison, participants in regional and remote settings spoke about the shortage or in some cases the scarcity of any form of mental healthcare service.



Results

RECOMMENDED RESEARCH FOCUS

Grief and loss including the impact of unresolved grief being passed on through the generations of a family, known as intergenerational grief

Behavioural and developmental issues in children

Mental health, including acute mental health episodes linked to substance misuse, depression and anxiety as well as suicide

Relationships between substance misuse, sexual abuse and loss of spirit

Loss of spirit and loss of hope and the feeling that there is no future

Services which would support the social and emotional wellbeing of children

Impact of disruptions caused by grief and loss, mental health issues or substance misuse on family and family life

Monitoring of clients' medication regimes

Appropriate social and emotional wellbeing models

Resources including funding required to provide appropriate and timely services

Theme two: Addictive behaviours and substance misuse

Addictive behaviours and substance misuse were considered to be pervasive, underpinning a range of health and social issues within some communities:

Safest place for a hamburger and three litres of wine is in your stomach apparently. So they get a cask and just skull the whole lot. Get another one, skull it. You're drunk for 24 hours. You don't even have to carry it. It's brilliant. It doesn't do your kidneys any good. Interviewee

Alcohol was often the substance of choice in these areas but other types of addictions were discussed, including gambling. Participants believed that some communities were overwhelmed by additional related problems, and did not know how to deal with the resulting issues:

Cigarettes are a social event. If you've got cigarettes you've got a bit of power or something. Run over there and get me some coffee and I'll give you two cigarettes. Hey, no worries. You can make people do anything

for a cigarette. Marijuana, you can make them strip your car engine down [laughs]. Yeah. But it's – and because it's economy in itself, it's gonna – they're going to keep buying it.' Interviewee

Addictive behaviours and substance misuse were relevant to not just the health sector but also education, housing and family and community services. While all age groups were implicated in and impacted by substance misuse, participants were particularly concerned for the wellbeing of children:

From my experience... it's always trauma or they've turned around and just seen it and grown up with it, like I said, because of alcohol. And then turned around, and it leads to marijuana, which leads to something heavier sometimes, not all the time. And I suppose make sure you get your child diagnosed if they're ADD or not, otherwise it will turn around and lead onto bigger things... Interviewee

Participants acknowledged a lack of culturally appropriate support and rehabilitation services for people attempting to overcome substance misuse and addiction. The lack of services aimed at supporting women was considered to be of particular concern. Misuse of prescription drugs was another emerging issue. However, it was not clear whether this related to over-prescribing by doctors or to 'doctor shopping' by patients.

Inter-regional differences

Once again, access to services became the main point of difference between regions. For urban participants the primary concern was the cultural appropriateness of the existing mainstream service. In regional areas, the reliance on part-time counsellors working from a primary healthcare service was of concern. Regional participants also discussed how they often provided care for remote clients (from outside their region). Regional participants also spoke about people travelling from remote to regional areas in order to access alcohol, particularly when their remote community was deemed a dry zone. This not only increased the pressure on regional services who were already struggling with a lack of staff



and other resources, but also meant that patients were undergoing rehabilitation away from country, community and family supports.

The other noticeable inter-regional difference was the types of drugs being used. In urban areas everything from smoking and alcohol to hard drugs such as methamphetamines were discussed. Heavier drugs, although not specifically named, were also referred to by participants in regional communities. Yet in remote communities, the drugs of choice appeared to be limited to smoking, alcohol and gunja (marijuana).

RECOMMENDED RESEARCH FOCUS

Addictive behaviours and substance abuse which have significant impacts on community and families

Suitable rehabilitation services that meet the cultural and family needs of Aboriginal people

Appropriate follow-up services to prevent a relapse back into substance misuse

Prescription drug abuse and particularly whether this was because of over-prescribing by doctors or doctor shopping by patients

Theme three: Cultural, social and environmental impacts on health

The interconnectedness of education, transport, housing, income and health and wellbeing was continually reinforced:

I mean obviously you know in life, some illnesses, they're just – unfortunately you can't do anything about them. But I think a lot of our issues go – you – you can treat the illness, but you've – you've got to also treat those other issues; the housing, the environment. All of that. Interviewee

Organisations other than health services were believed to also be responsible for health outcomes in the community:

It's a bit of everything really, whether it's employment, whether it's housing, whether it's transport. From a health perspective I'd say chronic disease... We've got a lot of chronic disease clients that don't manage their chronic disease correctly or efficiently.

A lot of them didn't even know these things existed before they came here and got diagnosed, so there's not enough education in the community I guess... we try to educate as best we can onsite through doctors and health staff, whether it's nurses or respiratory nurses or dieticians. We've got visiting people that come here through community health, which is quite excellent. But other than that, as I said, education's not so bad anymore in schooling... Employment is still an issue. It has been for a while, but I think that's mainly due to lack of qualifications. And... transport and housing. That's always going to be an issue. Transport mainly because obviously there's the bus service, but taxis are quite expensive... Interviewee

There appeared to be a number of challenges which were of particular concern in remote areas such as clean water, general hygiene, income, housing and language barriers:

Environmental health issues. Pest control. We've got massive cockroach infestation in those housing estate areas that are described in housing policies as their responsibility. And because of the sharing that happens of clothing, they're – they're breeding, they're going along from house to house and they're even found in cases of mobiles phones, the eggs. Interviewee

In addition, while resource-sharing was seen as a positive and important part of Aboriginal culture, some of the obligations that come from resource sharing created additional strains on already scarce resources. Participants described an attitude of 'use it while you can' in terms of food and alcohol in particular, before someone asks you to share this with them:

The biggest problem... this place has is... they call it humbugging, but it's begging basically. So a group goes into town, drinks all their money... They come out here, go round to the auntie's house, eat all their food. The auntie comes round my house, because I've got a job, and I'm basically feeding alcoholics and then that leads into – so if I've got this drink, right. I can't sip it. I have to skull it. So the



Results

safest place for two casks is in your stomach see. So everyone – that creates binge drinking. And then food, everyone is going to come and get my food. Everyone is, you know, so you binge eat all the time. You're looking at a place where everyone's your cousin and no one's got a job. Interviewee

Participants were frustrated that negative social and environmental impacts on health continue to remain a problem in Aboriginal communities. They believed that sufficient research identifying the cultural, social and environmental factors which impact on health, had already occurred. What was missing were clear strategies for ensuring these findings make a difference to the health and wellbeing of Aboriginal people. This may involve understanding how the findings are implemented within a practice setting.

Inter-regional differences

Participants from urban centres focused on homelessness and the growing need for affordable accommodation and housing. Poverty, as a result of difficulties in finding a job, together with a recent increase in the number of people who are poor because they are underemployed, meant that many people in urban settings could not always afford private rental accommodation. In regional centres, the quality of housing and expenses associated with maintaining a house, such as heating, was discussed. While similarly concerned with the quality of housing, in addition, participants in remote areas focused on issues relating to overcrowding. These remote area concerns were further exacerbated by poverty, primarily resulting from the lack of employment opportunities.

Regional differences were also noted in relation to transport. There were few references to transportation by urban participants. In contrast, Aboriginal people in regional and remote areas often found it difficult to attend healthcare appointments because they were unable to afford their own private transport and did not fit the criteria for the transport assistance scheme.

RECOMMENDED RESEARCH FOCUS

Developing clear strategies on how Aboriginal culture and social and environmental factors can make a positive difference to health and wellbeing

Housing and health impacts

Association between education and long-term health outcomes

Access and transport

Socio-economic disadvantage

Access to equal employment opportunities

Violence, including domestic violence, family violence and lateral violence

Discrimination and racism

Environmental and essential services

Prisoner health

Cultural determinants of health

Theme four: Control over food availability and choices

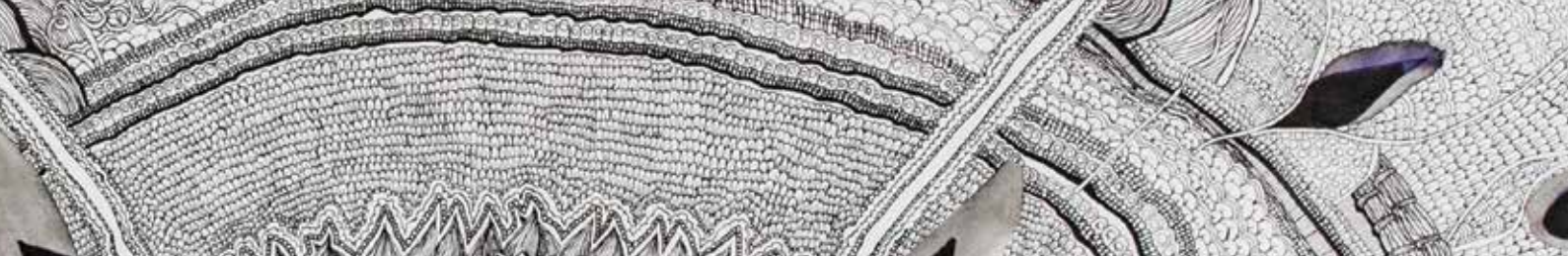
There were two primary sub-themes within the theme relating to food – those that were expressed as something that could be controlled and those that were expressed as issues which could not be controlled by the individual and/or their community. The controllable sub-theme included perceptions that some people chose not to eat well:

Lack of exercise, smoking, fatty foods. Luckily, here, we like fish and chips once a week normally or twice a week if you're lucky but then Kentucky Fried Chicken, there's all kinds of crap that people eat but, again, it's their personal choice, I guess. Interviewee

Participants were particularly concerned that some people behaved in a way that could further damage their health by consuming foods such as pies, coke and lots of sugar:

Sugar as I call it, the white death. Interviewee

I've seen people – I had a – a lady in here yesterday who's on dialysis three times a week – walking in here with a massive greasy



hamburger. The amount of Coca-Cola that gets drunk. It's huge. People are addicted to the stuff. Interviewee

There were comments made by participants pointing to the effects on health caused by colonisation and the changes in diet:

Go back to what they eat before, traditional type foods. Because – we see pictures of black fellas back in the day, looked like Greek statues. And so I think we're genetically prone to eat meat more than anything, but now when you get lamb it's got that extra – it's got a different fat. Interviewee

Hypertension, again, it's attributed to lifestyle. It's lifestyle change. It's difficult because it's been a presence there, people have grown up with certain foods, they eat certain foods, they gain certain habit lifestyle and – like myself, I've got diabetes. Interviewee

There was also recognition of the dilemmas many families face between choosing affordable food over nutritious food, which according to this participant, were mutually exclusive:

So, I suppose, that whole thing about how can you feed your family in a way that's nutritious and feeds everybody, and that whole food thing has such a big impact on so many other things, mmm, yeah...The food is really expensive, and so what you buy is all that cheap stuff and why wouldn't you go to McDonalds, 'cause you could buy a Happy Meal and get a toy for your kids and it's – there's nothing in it, mmm, yep – being really, really unfair. Interviewee

The relationship between food availability, food choices and chronic diseases was identified as the main question for future research.

Inter-regional differences

A major concern in rural and remote areas was the lack of control over the availability and affordability of food:

They get their food brought out on a truck and it's really expensive for them, and once

they buy their food – I mean, you only can buy a – a box full of food and that's all your pay gone, because it's so expensive. Yeah. And they are struggling to – to feed their kids then.' Interviewee

There was a greater emphasis on food and nutrition in regional and remote areas. In addition to discussing the disincentives to healthy eating, such as the availability and affordability of healthy food, participants in regional and remote settings also acknowledged the need for continuing education.

Finally, there was the recognition that people in remote areas did not always have the ability to purchase and store fresh produce, which inhibited their dietary choices.

RECOMMENDED RESEARCH FOCUS

Relationships between food availability and affordability, food choices, chronic disease and education

Theme five: Health conditions

Diabetes received the most attention by participants when considering health conditions. Yet in some interviews, diabetes was perceived as an accepted part of life:

We're seeing children as young as 12 with type 2 diabetes. Interviewee

A lot of people are diagnosed early with diabetes and don't feel any different and it's just a progression of the illness over time without medication or treatment that they sort of get to a point in their life where they end up on dialysis because of the progression of the illness. So I think it's more just education 'cause a lot of people sort of think, oh, well I'm just getting old but at 36, you're not old Statistically as Aboriginal people we are but yeah, people just put it down to feeling tired as I'm getting old I'm tired and worn out type of thing and without the understanding that it's the actual illness that's causing all of these feelings. Interviewee



Results

Complications from diabetes were discussed at length and while it was noted that treatment options are often available, the appropriateness of these options was unclear.

I mean that's the scary thing. I mean you've got a 35 year old ending up on dialysis and a 24 year old in intensive care with heart disease. So there's not one area I think 'cause everything sort of stems from the diabetes or the heart disease. Interviewee

Likewise, communicable diseases such as rheumatic heart disease and eye, ear and skin infections, particularly those affecting children, were a particular focus of a number of discussions. Other health conditions which concerned participants included: cancer, cardiovascular disease, obesity (in both adults and children), blood-borne viruses, human immunodeficiency virus (HIV), asthma, as well as the frequency of co-morbidities and multi-morbidities.

Participants also acknowledged that some people waited too long before choosing to access care, which in turn influenced longer-term physical health outcomes. While there was no sense of surprise with regards to the conditions requiring attention, participants were both disappointed and frustrated that often preventable chronic diseases remained a problem for many Aboriginal communities.

Inter-regional differences

While chronic diseases, such as diabetes featured in every interview, participants in regional and remote settings tended to emphasise the negative impact these had on the community as a whole.

Participants in remote communities spoke about the need to go into 'battle' over the prevalence of these conditions and how communities had been rocked by a number of recent deaths due to chronic disease.

PRIORITY CONDITIONS FOR RESEARCH FOCUS

| |
|---|
| Diabetes |
| Cancer |
| Cardiovascular disease |
| Asthma |
| Obesity – related to adults and children |
| Childhood illnesses, including early onset of chronic disease |
| Blood borne viruses |
| Co-morbidities and multi-morbidities |
| HIV |

Theme six: Promotion, prevention and healthy living

Knowledge about healthy ways of living was recognised as important, but the value of healthy ways of living was also noticeably missing in some communities:

Lack of exercise. Driving from your house to the shop for example. Someone walked down this middle street, knocked on my door when I had a car here. But I gave my car to my niece, beside the point. Knocks on my door and goes, 'Can you drive me to the shop?' Well, if you walked you would have been at the shop. [Laughs]. He can walk all the way down my street. Crazy. And your ancestors used to walk across the [swears] Nullarbor and you can't even walk to the shop. Interviewee

Yeah. And – and it come back to some simple things as well like – like making sure children blow their noses. And – and back to hygiene and environmental issues as well. And home hygiene, you know, swiping things down, wiping door handles so they're not picking up so many infections and things like that, yeah. Interviewee

In particular, there was an emphasis on the differences between behaviours that involved taking risks and those that were understood as being more protective behaviours.



And... we've had a lot of deaths along (a road) where people have been intoxicated and hit by cars in a very dark area. And again, coming back to local policies, they've been forced – council policies, they've been forced to walk on the road instead of cutting across pieces of land. Things have been blocked off so they couldn't get through. So they're onto the road. Obviously they're dark-skinned, they're wearing dark clothing, they're not visible. Interviewee

Participants spoke about how some people seemed to have entrenched ideas or ways of thinking about their health that were almost beyond their control and resulted in unhealthy behaviour. This led them to wonder how these ideas, or ways of thinking, could be changed and lead them to greater control over their behaviours or attitudes, which would be more conducive to better health.

Participants spoke about a need for culturally appropriate, healthy living and parenting programs within some communities. In particular, the importance of parenting roles in the early years (including the prenatal stage), in order to ensure that people grew up strong, was highlighted. Providing parents with an understanding of what it is they need to know and how to ensure their children were healthy was considered to be important. It was also noted that participants tended to confuse health education (health literacy) with prevention and health promotion, not always seeing these as different approaches. As a result, these categories were very much interwoven, making it particularly difficult to discuss them as separate issues.

Inter-regional differences

In line with the overarching theme of growing up strong and healthy, the importance of education about parenting roles was a particular focus for participants in regional areas. It was believed that education needed to start with pre-teens and should include boys as well as girls. Participants from regional and remote communities suggested

that healthcare providers should consider new ways of promoting health and healthcare services which accounted for varying levels of English language literacy.

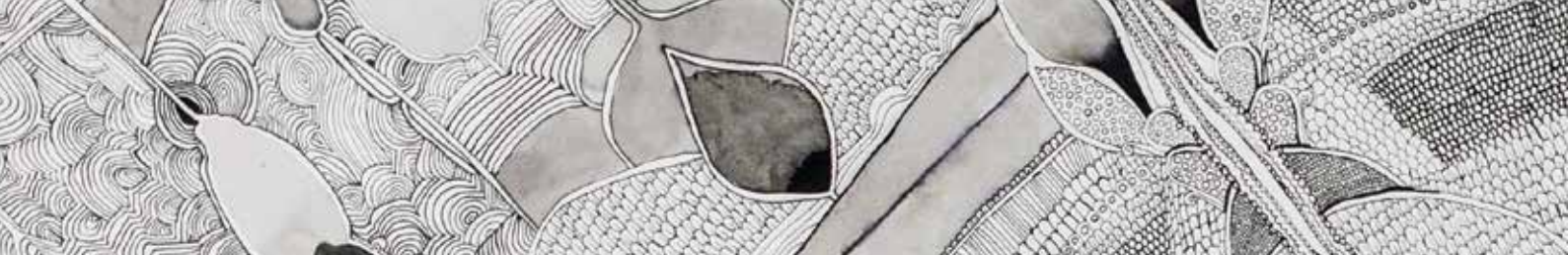
RECOMMENDED RESEARCH FOCUS

| |
|---|
| Healthy living, including nutrition and lifestyle factors |
| Early intervention and prevention |
| Follow-up care including post-operative and prevention of co-morbidities |
| Participatory action research focusing on the difference between health literacy, health prevention and promotion |

Theme seven: Community empowerment and leadership

The focus on Aboriginal community empowerment in order to build healthy communities, particularly in relation to the social and emotional wellbeing of the community as a whole, was particularly strong. This was especially important in communities whose hope and motivation for a healthy future were diminished. In communities where Aboriginal community controlled health services existed, increasing the levels of community empowerment and leadership were considered essential. This theme was also directly aligned to the cultural determinants of health as well as the social and emotional wellbeing themes. A lack of hope and constant worry in a context of dispossession and Aboriginal cultural practices of sharing resources, for example, can impede empowerment and obstruct leaders from emerging:

Sitting at the table, trying to get communities to come up with their own solutions around intoxication. It is difficult to break through it because we don't have enough counselling to deal with the grief and loss. There's a group of... hard core people who would be hallucinatory... who are sleeping rough. There's been a big coronial enquiry into that. That's not improving. There is lack of housing. Lack of shelter... they – some of those are big drinkers. Those are elderly people. But their



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BSLs and their overall health is not too bad because they've got good care, good shelter and access to good food. So what it is, is lack of hope. It's lack of hope. And it's – it's a massive problem because it's – people are migrating into this community. This community doesn't want them. So a lot of talk is, well get a bus and send them back... (But) Okay,... send them back to what? So it's lack of shelter. It's lack of acceptance. It's allowing people to go out there in the mangroves and drink there. It's worse than third world organised slums. And I think the other parts of intoxication are difficult to deal with because there is just a general lack of hope. Interviewee

Inter-regional differences

Community empowerment and leadership were important concepts discussed by participants from both regional and remote settings. In regional centres, participants chiefly spoke about the need to have the right person to lead the community and the importance of providing information so that community members could make decisions for themselves.

Regional participants also spoke to the importance of 'hope' to empower community members. Participants from remote communities focused on issues of leadership as well as the importance of ensuring that local people who knew the local context held these positions. According to participants from remote communities, having the right leader resulted in a move away from relying on handouts to one of community self-sufficiency.

RECOMMENDED RESEARCH FOCUS

Community empowerment, including capacity building and promoting leadership

Community morale, including reducing passivity and encouraging leadership roles

Enhancing communities' hopes for the future

Theme eight: The health system and strategic health policies

The main concern expressed by participants when considering strategic health policies was the lack of connection across the health sector from mainstream health services to ACCHOs. Workers who specialised in providing services for drug and alcohol issues were frustrated by systemic constraints on their capacity to provide an adequate service to their clients. For example, there were particular concerns about the impact of a litigious and risk-averse environment on government workers, which resulted in workers being micro-managed and having less time available to work with clients.

Inter-regional differences

While participants in urban areas tended to focus on the need for more flexible healthcare services, participants in regional and remote settings spoke about insufficient funding, the lack of healthcare services, and difficulties for patients to access some specialist services. There was frustration with not being able to influence policy decisions, which are made without an understanding of their remote context.

RECOMMENDED RESEARCH FOCUS

Workforce issues, including Aboriginal health workforce

Funding, including operational funding and disparities between rural and remote funding levels

Government and governance including increasing Aboriginal participation in policy, and enhancing governments' understanding of unique healthcare service issues in some regions

Provision of support for children's health, particularly around social and emotional wellbeing models of care

Pre- and post-natal policies, including opportunity for mothers to home birth

Commonwealth and State Governments accountability frameworks



Theme nine: Improving individual's access to services

A diverse set of interconnecting factors was seen to act as a barrier to accessing healthcare. The historical connection between services; policies such as removal of children and ongoing issues of racism were believed to hinder people's access to healthcare services. It was noted that there were often particularly hard-to-reach groups in many communities. Aboriginal men and those misusing or abusing alcohol or other substances were two groups that received particular mention:

Well, I'd say straight away it's – we need to understand how accessible services are, right from health services to education services and recreation services. And then... it takes care of everything, it takes care of the geographical location, it takes care of the financial strain it may put on, so yeah, it takes care of [knowing if] the services, adequate for the community.
Interviewee

People's opinions of a health service affected how much they accessed the service. If health service staff provided health treatments or interventions but were too busy to engage in health promotion or prevention activities, some people's knowledge about healthcare was limited to ideas about 'getting fixed'. Such notions potentially impacted on their willingness to access healthcare services for health promotion and prevention approaches.

Inter-regional differences

Participants from regional and remote areas called for better access to tertiary and specialist healthcare and focused on the lack of transportation to access services outside of their immediate community. Regional participants, in particular, noted that some people preferred dealing with mainstream healthcare practitioners, or services in other locations, due to the politics and privacy issues in smaller communities. Urban participants, in comparison, spoke about the difficulties with navigating the healthcare system, especially in relation to hospital and specialist appointments.

RECOMMENDED RESEARCH FOCUS

How to develop services for Aboriginal men and those who are falling through the gaps or are 'hard-to-reach' groups

Identifying the barriers to Aboriginal people accessing general health services, tertiary and specialist services

Determining pathways to increase access to care with particular attention on the differences for urban, regional and remote areas

Theme ten: Improving ACCHOs and mainstream health services

Discrimination and racism toward Aboriginal people in mainstream services, such as in hospitals and other healthcare services, was frequently discussed. Mainstream healthcare services were considered to be inflexible and the attitudes of some staff were inconsistent with ensuring culturally safe environments for Aboriginal people. In addition, the organisational culture within some mainstream services was not particularly welcoming or responsive to feedback from Aboriginal people and although a significant amount of feedback was provided, participants felt that 'no one was listening'.

There was the perception that in locations where an ACCHO existed, mainstream services tended to take less responsibility for the healthcare of Aboriginal people. Further, the propensity toward placing Aboriginal staff in mainstream drug and alcohol services was believed to limit the delivery of culturally appropriate care more broadly in mainstream services.

Compared to mainstream services, ACCHOs differences and benefits were mainly associated with them being community controlled, which formed the foundation for yielding multiple benefits, such as the provision of care that is culturally appropriate; a welcoming atmosphere; family-friendly and client-centred models of care that were innovative and flexible in design and delivery. These benefits were understood as fostering and sustaining relationships with the community by employing Aboriginal staff and directly supporting a sense of community belonging and ownership.



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However, among the challenges and issues of concern for ACCHOs were community politics and conflict, and inter-family dynamics. Participants believed that ACCHOs needed to find ways to work around these issues to ensure that all Aboriginal families in a community were welcomed into their local Aboriginal health service.

Another set of challenges that concerned the Aboriginal health workforce was the need for more motivated and skilled staff that could work in functioning teams with the Aboriginal community. A functioning team was considered to be one that ideally included Aboriginal workers, who proactively showed initiative and worked together to fill perceived gaps in healthcare and service delivery. Aboriginal workers were trusted to perform this role as they lived in the community and therefore, knew a lot about it. These levels of trust and knowledge were particularly relevant in remote areas among smaller communities. However, because they lived in the community and were trusted, participants identified burnout as a significant risk for Aboriginal workers, as they were often unable to leave the urgent or complex problems of clients behind them in the workplace. Burnout was a particular risk in smaller communities, where there were inseparable boundaries between the workplace, home and the community. Such situations heightened stress levels and the potential for burnout as people's personal lives overlapped with their work. These concerns were reported to keep them awake at night. Sleep deprivation, stress and anxiety are known to negatively impact on motivation in the workplace and contribute to fatigue and breakdown, or burnout.

The capacity of ACCHOs to cope with more than just basic care was understood to be limited by a lack of funding. Funding determined the extent of service flexibility and ACCHOs often provided services they were not actually funded to deliver. There was also a concern about ACCHOs being more accountable with funding allocated to health service delivery to the community. To reinforce the need for healthcare services, ACCHOs needed to more effectively capture

and present the evidence of the healthcare they provide. Participants believed that ACCHOs were caught between trying to meet the requirements of the community while also struggling with an inflexible healthcare system and insufficient resources:

Yeah, I've seen a number of pilot projects start up and they start up with nominal funding but they're destined to fail because they have no longevity planned. They have no sustainability so – and the only projects that I've ever seen work or have any substance or sustainability are the ones that have ongoing funding but have the necessary resources to make them work long term. Interviewee

Health system and service improvements that were of particular concern for participants covered three main areas. First, the need to focus on prevention and early intervention through health promotion and education activities, better opportunistic screening and proactive health checks was identified. Second, models of care that can accommodate a holistic approach, promote continuity of care and better use of specialist and other services should be developed. Finally, administrators should be supported to capture feedback for continual improvement.

Inter-regional differences

With regards to improving ACCHOs, participants from regional centres were particularly conscious of the need for culturally safe healthcare environments that are free from racism. They believed culturally safe healthcare was provided by ACCHOs. They also noted how difficult it was for their smaller ACCHO counterparts in remote locations to provide services, given the limited funding they received. In remote communities, participants spoke about having to meet the needs of several, quite diverse communities, which added to the pressure of stretching already scarce resources.

Concerning improving existing health services, participants in urban centres spoke of the need to simplify the way in which people navigate the healthcare system. Other issues, which



concerned urban participants, were greater emphasis on developing and providing services for young people. In comparison, participants in regional and remote areas tended to focus on the general need for more services as well as more resources to support existing services.

RECOMMENDED RESEARCH FOCUS

Cultural safety within mainstream services

Increasing flexibility of mainstream services to meet the needs of Aboriginal people

Identifying ways in which ACCHOs have more say in how they are operated

Identifying family-level and community-level conflict resolution approaches to ensure ACCHO services can be accessed by all Aboriginal families in a community

A holistic healthcare model which is coordinated and resourced appropriately to include continuity of care and access to specialist services

Increased Aboriginal management and control

Prevention and early intervention through health promotion and education activities

Identifying opportunistic screening and proactive health checks

Developing data collection systems for use by ACCHO administrators for quality improvement

How should research involving Aboriginal people be conducted?

Analysis of the interviews concerning the conduct of research focussed on the following four questions:

- How did participants describe their research experiences?
- How has research impacted on health services and Aboriginal communities?
 - What positive impacts were discussed?
 - What negative impacts were discussed?
- Did participants feel comfortable saying 'no' to research, and why?
- How did participants think future research should be undertaken?

The findings from each question are presented below:

Question one: Participants' descriptions of research experiences

Positive prior research experiences were generally described as being 'pretty good', particularly if their experience included:

- An affirmation of local knowledge and honest feedback was provided;
- Following protocols led to participants thinking the research was culturally respectful;
- A direct and tangible outcome or benefit to the community was achieved;
- A relevant research focus;
- Sharing of the knowledge gained with ACCHO staff;
- Gaps in knowledge or services identified and future direction(s) proposed;
- A networking benefit when research findings were used to help services learn from one another and this, in turn, reduced their sense of isolation, either physically or because of the research topic; and
- Building the capacity of staff or Aboriginal community members.

Where several of the above positive elements combined, an empowering effect was felt for individuals, organisations and communities.

Negative research experiences were understood at an individual, organisational and general level, depending on the scope of the topic and whether the results or changes were actualised or seen. At an individual level, research was difficult if it was considered intrusive and invasive of personal time, space and privacy, especially during crucial times of life when privacy is valued. Examples included during early parenthood or close to major life events or stressful times such as grief or loss.



Results

Communication or correspondence methods used by researchers were criticised. Unless the topic was thought to be relevant to specific community needs or reflected what the community felt was important, it was negatively viewed. Consulting with the community and providing more feedback written in plain English could counter such negative experiences.

At an organisational level, participants were affected by research fatigue, which led to feelings of apathy about research. Frustration and annoyance were expressed over the amount of time research took, especially if the research was considered too intrusive; repetitive; a burden on the organisation's overall capacity, or if it consumed precious resources. It was also commented that the relative strength of an organisation could ensure the proper conduct of research. If the research was located in remote areas, the drain on organisational resources was particularly noted. Another concern was when ACCHO contributions were not acknowledged, or when the authority of the ACCHO was undermined by the actions of researchers to 'go around' the ACCHO, if for example, the ACCHO had not supported the research.

At a general level, ill ease about research occurred if the benefits of research were judged as being short-term or artificially inflated by the researchers; if the researchers made assumptions, which were inappropriate or inaccurate; or if it was thought that the research reflected the self-interest of the researcher. Some participants observed that, as a methodology, quantitative research often reflected a lack of understanding about the diversity of Aboriginal people and communities. This could have potentially negative implications for the development or targeting of programs, which may have been devised from using quantitative methodologies that did not understand or reflect the diversity and different needs of individual communities.

There were instances where experience of research was mixed, and included both positive and negative feelings. Some participants were ambivalent yet hopeful about research. Attitudes varied according to the methodology, where qualitative methodologies were preferred for being able to 'tell people's stories' and participatory action research

was viewed positively as it was more likely to make a difference. On the other hand, quantitative studies were often thought to be flawed due to a perceived inability to reflect the diversity in Aboriginal communities. Finally, participants were cautious about being audio-taped. They expressed the view that monetary reimbursement for participation in research could be problematic, particularly if the money then acted as an incentive to participate in any research project or where the money was used for the purchase of alcohol or cigarettes, for example.

Question two: Impacts of research on health services and Aboriginal communities

The main positive impact of research was when it led to the greater likelihood of a program being continued or sustained into the future (eg: evaluation of programs). Several negative impacts were discussed, including:

- Too little or no consultation with the Aboriginal community;
- The time commitment having too much impact on organisational capacity;
- Limitations to the scope of the project; and
- If the findings and feedback were not disseminated to the organisation or the Aboriginal community.

Some Aboriginal communities were fearful and concerned about research, leading them to feel unsure about the impact it might have.

Question three: Comfort with saying 'no' to research and why?

Participants were asked about their level of comfort with saying 'no' to research because of numerous instances of poor consultation and engagement by researchers, which have led to a general sense of disempowerment in the ACCHO sector. The findings to this question indicate the majority of participants felt comfortable saying 'no' to research (N=42). There were equal numbers of participants who felt uncomfortable saying 'no' (N=6) or were ambivalent about saying 'no' (N=6).



Participant's reasons for saying 'no' included being unconvinced the research would benefit the Aboriginal community, individuals or the organisation by providing real and sustainable change. Many felt that they had to be assured in their own mind that the research topic was relevant and would make a difference. The research needed to be conducted ethically, professionally and by competent and respectful people – who behaved appropriately and unobtrusively. Participants gained a sense of empowerment in saying 'no' to research.

Service providers or Aboriginal health advisory member participants felt it was their role to protect and to advocate for the Aboriginal community. There were a number of organisational reasons for being comfortable about rejecting involvement in research, including concerns about the burden of research in terms of time pressures, having other immediate priorities, staff capacity and when it was not in the best interests of the organisation or being bad timing for the organisation. There was a sense that Aboriginal people were over-researched or that research was repetitious.

Participants who felt uncomfortable saying 'no' to research did so for personal, community-level and organisational reasons (N=6). Some people felt uncomfortable about saying no as they questioned what they could contribute, were worried about giving 'right' or 'wrong' answers or felt pressured or encouraged by others to participate. At a community-level, those who felt uncomfortable saying 'no' to research appeared to be motivated by altruistic reasons. If they refused to participate, they thought it would be a lost opportunity to contribute, and learn or understand more about health or other issues affecting Aboriginal people. The organisational-level responses were concerned with ideas about corporate responsibility, such as it being a part of the ethos of the organisation to be involved in research, as without research it is harder to know what's going on or to understand the diversity between Aboriginal communities.

Ambivalence (N=6) about saying 'no' to research was mostly expressed by the participant weighing up the pros and cons of being involved. For example, if they agreed to take part it provided the opportunity to understand or know more about the research topic, or to gain a benefit from the

research. Saying 'no' was weighed against the likely burden of being involved in research. In these cases, there was no outright answer.

**Question four:
How should future research
be undertaken?**

There were suggestions from interview participants about the mistakes or inappropriate approaches used by researchers, as well as ideas about what future research should focus on, as far as possible.

RECOMMENDATIONS FOR RESEARCHERS

- To respect the authority of ACCHOs and to do their homework on the organisation, Aboriginal population and local area
- Find out about cultural protocols and follow them
- Seek guidance from an Aboriginal cultural mentor
- Be prepared to drop their own (or industry) agenda(s) and consult with Aboriginal people to find a topic of benefit to Aboriginal people which is relevant to community needs and therefore more likely to produce a tangible outcome
- Seek advice on the most appropriate way of recruiting participants
- Submit all research proposals for ethical review by the AHREC
- Work in partnership with Aboriginal people to empower them and build their research capacity
- Minimise or make every effort to reduce the burden of research on an ACCHO and on individuals
- Be informed about the circumstances of ACCHOs and have realistic expectations, especially if the research is located in remote areas
- Use appropriate communication and correspondence methods and not use academic language
- Exercise common courtesy by respectfully asking questions, rather than being demanding, self-interested or unpleasant
- Tread extra carefully if the research concerns sensitive issues or is likely to occur at crucial time of life
- Provide honest feedback on the findings and organise networking events aimed at sharing knowledge with the Aboriginal community, participants and with ACCHOs. Acknowledge everyone's input



Results

Main findings from the Consensus Workshop

A consensus workshop was held in Adelaide and attended by a total of 37 representatives from across South Australia, who included ACCHOs (N=12) and AHACs (N=12). The purpose of the workshop was to present the main findings from the interviews and seek consensus on a final list of research topics for the ACCHO sector which reflected both local and statewide priorities. The agenda for the two-day workshop is included in Appendix 6.

Participants were presented with the background of the project, an outline of the role of research, the study methods used in Next Steps, the findings of the audit and current issues of concern as identified from the interviews. Participants then formed into five smaller groups for a facilitated workshop. They were grouped according to their geographical regions or links and two facilitators led each group. The facilitators were from the Research Team, Co-investigators or Wardliparingga Aboriginal Research Unit support staff.

The aim of the small group sessions was to discuss and then provide feedback on the overarching findings and main themes that were identified through initial analysis of the semi-structured interviews. This included what the findings indicated for their local regions, what stood out as important, what was missing, and how research could be improved and more effective in their regions.

Participants provided overall consensus on the 10 major themes. Importantly, participants reported that the themes were all interconnected and should be looked at holistically, reiterating this point by stating that no theme was any less important than another. Notwithstanding these comments, there were a number of emerging issues which were raised and discussed at the workshop.

Participants reiterated the importance of health promotion in relation to raising awareness of health conditions, how they could be prevented and the promotion of healthy lifestyles, with a focus on healthy eating.

The importance of having strong governance structures and leadership within communities and the need for building community empowerment was highlighted. Particular mention was given to the relationships between ACCHO governance committees and staff working on the ground and the need for these relationships to be strengthened. Participants discussed the existing tension between corporate governance (business models) and community governance. It was stated that Aboriginal people have many answers to issues affecting their communities; however they often felt they were not listened to or were not empowered to lead research priority setting. The view that education is extremely important and is a vital contributor to the empowerment of communities, was also a focus.

In terms of how to conduct research better, it was emphasised that research needs to be conducted in an equivalent intercultural partnership where reciprocity and equal learning are priorities and the diversity, skills and knowledge of Aboriginal people are acknowledged. Participants believed that it was the responsibility of the AHREC to ensure that Aboriginal people are included in the establishment of research questions, with engagement and communication being critical factors. Furthermore, research should not take place unless it includes capacity building for Aboriginal people by involving the local community, to ensure more Aboriginal people are supported to undertake higher degrees enabling an increase in the number of Aboriginal people leading research studies.

More communication between the AHREC and communities is needed. It was also stated that researchers must look to prior research to avoid duplication of research and utilise positive learnings from other studies, particularly in relation to how to appropriately liaise and consult with Aboriginal people and to respect the community's right to say 'no' to research. Participants talked about the importance of sitting down and talking to Aboriginal people in order to establish their ways of doing research. Ensuring that plain English is used and that local community protocols are followed was also highlighted, as was the importance of maintaining engagement with the community and providing feedback. Consideration was given to the development of specific guidelines within



individual communities to ensure that researchers conduct themselves and the research appropriately. An accreditation process for researchers was put forward, along with the need for a national level agreement to ensure that research questions are viewed prior to funding being granted.

Capacity building and workforce were raised as important issues. In regions where there was no ACCHO, there was concern about overburdening Aboriginal Health Workers (AHWs) working in mainstream services and the need to increase their number and strengthen the support available to them at the local level.

There was a strong focus on the fact that young people make up a high percentage of the overall population in Aboriginal communities and the need to educate, encourage and support them. It was also suggested that a buddy system be introduced to provide young workers with supportive role models and that investment should be put into Aboriginal people who have particular skills in leading young people. Participants reiterated the need for more male health workers to be employed in health services to provide a gender balance and to contribute to better health outcomes for Aboriginal men. There was also a strong focus on the need for more Aboriginal registered nurses.

Participants talked about the range of barriers facing Aboriginal communities and their frustration with governments who shelve reports they believed were 'too hard' to implement. Such actions lead to the sense of there being little or no accountability from government, in contrast to the accountability requirements of ACCHOs. Participants believed that research needed to begin with looking into government processes and policies, as government drives and funds research and should therefore be open to external scrutiny.

Emphasis was given to colonisation in Australia and its ongoing effects of long-term disadvantage for Aboriginal people, particularly in terms of health and wellbeing and how this needed to be addressed before any real progress could be made.

Participants stated that mental health and social and emotional wellbeing needed to be separated. They discussed the stigmatisation of mental health and how 'mental health' is used instead of 'mental

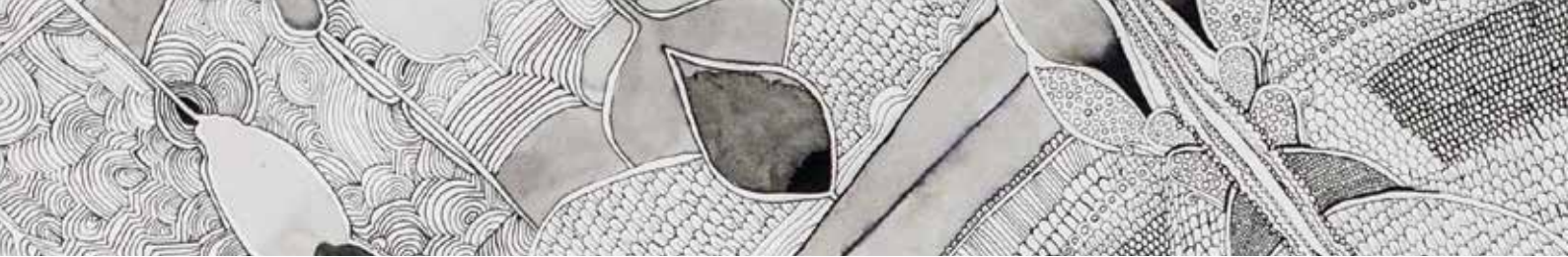
illness', which usually entails a diagnosis. Loss of identity, loss of spirit, grief and loss, trauma and loss of family or community roles and structures can significantly affect Aboriginal people's social and emotional wellbeing. It was also conveyed that there needs to be increased awareness and literacy around mental illnesses. Youth suicides were highlighted as a continuing major concern for participants and the Aboriginal community, and the need for support services and networks for families, was strongly expressed.

In terms of service delivery, participants reiterated particular concern for young people and the existing, critical window of opportunity to make a difference in their lives. Similarly, other critical opportunities were during women's antenatal care, especially for those who smoked tobacco and consumed alcohol during pregnancy; the general management of conditions, lifestyles, infants and children up to the age of three. In relation to these concerns, the need for adequately funded, accessible services, longer-term funding, appropriate and effective models of care and the need for service integration was also highlighted.

Participants advised that the findings from the Next Steps research project should be used to empower Aboriginal people and it was suggested that a website be developed to advise researchers on how to conduct research with Aboriginal communities, what issues need to be addressed and who to consult with.

A number of research topics, which participants believed would be of benefit to Aboriginal people in South Australia, were proposed in the small group discussions. These topic areas, summarised in the table on the next page, relate to the main themes from the interviews. These themes were presented to participants and discussed in the consensus workshop.

The issues raised under each topic area have been incorporated into the key results represented by the model of five main health and medical research priority areas. As such, these topic areas lend themselves to further development by researchers in collaboration with the ACCHO sector and Aboriginal people.



Results

Research topics from Consensus Workshop

STRONG AND HEALTHY BABIES, CHILDREN AND YOUNG PEOPLE

What factors are affecting the health of our children?

How does nutrition, foetal alcohol syndrome and maternal health affect children's health?

Do youth programs work? How and for whom?

What contributes to youth wellbeing?

SOCIAL AND EMOTIONAL WELLBEING

Social and emotional wellbeing and trauma counselling: what works and what is available?

What are the differences in cultural, social and governmental determinants of health?

For example: What influence does education, transport, housing or income have in determining health?

HEALTH CONDITIONS

More understanding is needed of the range of factors that lead to the development of certain illnesses or chronic conditions, for example, diet and stress.

How can the propensity to develop certain illnesses or chronic conditions be minimised?

CONTROL OVER FOOD CHOICES AND AVAILABILITY

How should communities be resourced to grow and manage their own food?

What types of food choices and supplies do people want?

To what extent is food affordability an issue?

STRATEGIC HEALTH POLICY

How can successful programs and funding for these programs be sustained over time?

There is a need to explore how the short-term funding of AHWs can be improved, as current arrangements impact negatively on their engagement in the workforce and capacity to fulfil their role.

What are the benefits of long-term funding rather than short-term?



ISSUES FOR ACCHOS AND AHACS

How is quality healthcare defined from an Aboriginal perspective?

How do we get everyone together to work together more effectively?

An investigation into successful programs, interventions and approaches delivered by ACCHOs is needed and how these successes can be replicated in other communities.

How can we demonstrate that ACCHOs deliver better services?

What type of business model would ensure that communities benefit in a tangible way?

How can we improve the monitoring and evaluation of solutions?

A historical overview and evaluation of AHACs⁵ is needed.

MAINSTREAM HEALTH SERVICE

An exploration of institutional, mainstream and individual racism and cultural safety are needed.

How can interventions be secured when there are multiple disciplines and cross-sectoral responsibilities?

What strategies should be used and inputs are needed to get an appropriate intervention in these circumstances?

Are communities who are not serviced by an ACCHO satisfied with their local health services?

Are research findings reflected in government policies?

What policies or strategies could be taken to government to make a difference?

Research is needed into why governments don't appear to act on research findings and what happens to the findings.

How many Aboriginal people are in a decision-making role in state and Commonwealth government?

How do we elevate more Aboriginal people to decision-making roles in government?

⁵ 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.



Discussion

Research has an important role to play in improving the health and wellbeing of Aboriginal and Torres Strait Islander people. Yet, previous engagement between Aboriginal communities and research institutes have not always been positive, nor has research (or researchers) always delivered the benefits communities and individuals have expected. Recent years have seen the development of strategies and policies to better guide culturally aligned approaches to research for and with Aboriginal people, but reform has been slow to enact, and research for many remains a contested and unequal process. The Next Steps project seeks to directly change this through clearly documenting community priorities and acceptable methods for research.

This report could and should be used to guide the development of specific research that represents taking the Next Steps for Aboriginal Health Research. In order to do so, research into Aboriginal health must integrate the whole of life view embedded in the National Aboriginal Community Controlled Health Organisation (NACCHO) definition of Aboriginal health (NACCHO, 2006 <http://www.naccho.org.au/aboriginal-health/definitions>). A significant amount of research has previously been undertaken, aimed at improving the general health and wellbeing of Aboriginal people. However, communities are clear that the primary target of this work should focus on a holistic definition of Aboriginal health – targeted towards support for the development of 'strong and healthy families and communities across the lifespan', whilst understanding 'resilience, diversity and unique community needs' across a range of settings and locations.

Little achievement in health and medical research can be expected without supporting and contributing to a sustainable and adequately funded ACCHO sector. There was a strong sense from consultations that community controlled services act as the

central hubs for Aboriginal health and wellbeing within many communities, with representative and gender-balanced approaches to governance, an Aboriginal health workforce who are able to advise about, collaborate with and provide the essential links into Aboriginal communities for the proper conduct of research. Culturally appropriate health services are central to developing an Aboriginal-led research agenda for Aboriginal people. ACCHO's core role in delivering primary healthcare services and programs to the South Australia Aboriginal community must be supported through research that has an action and intervention orientation, particularly where health services research is planned. It remains critical that researchers understand that ACCHOs cannot be over-burdened by research, given the workload and resource constraints that ACCHOs must operate within. Furthermore, appropriate consultation and feedback is required before, during and after completion of a project.

The role of the Aboriginal Health Research Ethics Committee (AHREC) is vital to the proper conduct of research, but adequate resources are needed to monitor research activities and disseminate relevant research findings. The work of AHREC could be supported by reference to the findings of this project, especially in regard to how research should be conducted with Aboriginal people and communities. Researchers wishing to engage in Aboriginal research projects should familiarise themselves with the community identified priorities and processes outlined in this report. The expansion of the AHCSA website is needed to enable dissemination of all AHREC-approved Aboriginal health research projects and findings; as well as advising researchers on how to conduct research with Aboriginal communities, what issues need to be addressed and who to consult with. Above all, the main next steps required are the development and implementation of sustainable interventions for tangible improvements to the health and wellbeing of Aboriginal people.



Implications

This study has captured the needs and priority areas for Aboriginal health research from the Aboriginal community in South Australia at a particular point in time. A review in five years from the date of publication, to reflect on the impact of the findings on research in South Australia is recommended.

What do the findings mean for the Aboriginal community-controlled sector?

The South Australian ACCHO sector has benefited from participating in an inclusive, open and respectful process of identifying the issues that they consider are priorities for research and action. Knowledge and understanding of the connection between research and their everyday work in delivering services and care to their communities has been strengthened. Topics that are of most concern to Aboriginal people and the ACCHO sector have been acknowledged and documented along with more preferred ways of conducting research. In having had the IHRSS (2005) as a forerunner, this project has taken another step along the path to building the capacity of Aboriginal service providers and researchers towards more meaningful empowerment and engagement with research.

What do the findings mean for researchers?

The findings of the Next Steps project can facilitate engagement with the ACCHO sector and Aboriginal people and help guide the development of research topics in the future. In particular, the section on Further Research (detailed on the next page) emphasises the effort needed to translate research knowledge into tangible benefits as well as outlining topics based upon the needs and priorities of Aboriginal people.

What do the findings mean for universities or research institutes?

In addition to the points outlined above, universities and research institutes could use this report to encourage academic staff and students to be creative, but rigorous, in developing and/or utilising research methodologies more appropriate to improving the health of Aboriginal people.



Further Research

It is imperative that research efforts prioritise the development and implementation of sustainable interventions for tangible improvements to the health and wellbeing of Aboriginal people. There are significant research efforts being put into general health conditions, such as diabetes, cancer, cardiovascular disease and blood-borne viruses. However, topics such as obesity in adults and children; childhood illnesses, including the early onset of chronic disease; secondary prevention of co-morbidities and multi-morbidities; human immunodeficiency virus (HIV) and asthma receive less attention and represent potentially valuable areas for further research.

Studies are needed which connect all aspects of the social determinants of health, including healthy living (nutrition and lifestyle factors), housing, education, employment, social networks, connection with land, racism, the health of prisoners and law enforcement.

A greater understanding of all the factors that contribute to thriving infants and children (up to three years' of age) is needed. In relation to babies and children, the provision of support for behavioural and developmental issues in children, general child health and social and emotional wellbeing models of care, foetal alcohol syndrome, nutrition, antenatal and postnatal care (particularly in relation to women smoking tobacco and drinking alcohol whilst pregnant) need to be better understood. With regards to mothers and fathers, more understanding is needed on maternal health, home birth opportunities and mothers' social and emotional wellbeing, and the role of fathers. More research is needed on Aboriginal men's health issues, most particularly men's mental health, spiritual wellbeing and depression, as well as chronic disease.

Research is also needed to better understand what defines, constitutes and supports Aboriginal resilience. This is critical to support the strength of communities more effectively and to build upon this capacity both at an individual level and a community level. This could be linked to community empowerment and morale, capacity building, and ways to reduce passivity and

encourage leadership roles – all of which help enhance people's hopes for the future. Aboriginal people want to lead positive and fulfilling lives, however, the ongoing impacts of colonisation need to be understood as having contributed to long-term disadvantage for Aboriginal people, particularly in terms of health and wellbeing. The intergenerational dynamics of grief and loss, domestic violence, family violence and lateral violence and appropriate social and emotional wellbeing models need developing.

While they are sensitive and complex, addictive behaviours and substance misuse have significant impacts on Aboriginal families and communities and are other areas representing gaps in research activity. Topics within this area could include acute mental health episodes linked to substance misuse, depression and anxiety, as well as suicide; the relationship between substance misuse, sexual abuse and loss of spirit; suitable rehabilitation services that meet the Aboriginal cultural and family needs and appropriate follow-up services to prevent a relapse back into substance misuse. Anecdotal information provided during this study suggested that prescription drug abuse occurs from over-prescribing by doctors or by patients going 'doctor shopping'. The extent to which this is true needs to be established through research.

Challenges, particular to remote areas, included access to clean water, general hygiene, environmental and essential services, income, housing and language barriers. In rural and remote communities, concerns over the availability and affordability of food persist, as does the relationship between food availability, food choices and chronic diseases. The nexus of food and chronic disease was identified as the main question for future research. Broader issues of disparity were identified as aspects of funding, including operational funding, and the differences between urban, rural and remote funding levels.

All research efforts need to include Aboriginal capacity building. The ACCHO sector needs its own research funding to undertake studies on issues such as: governance (corporate and community); cultural determinants of health;



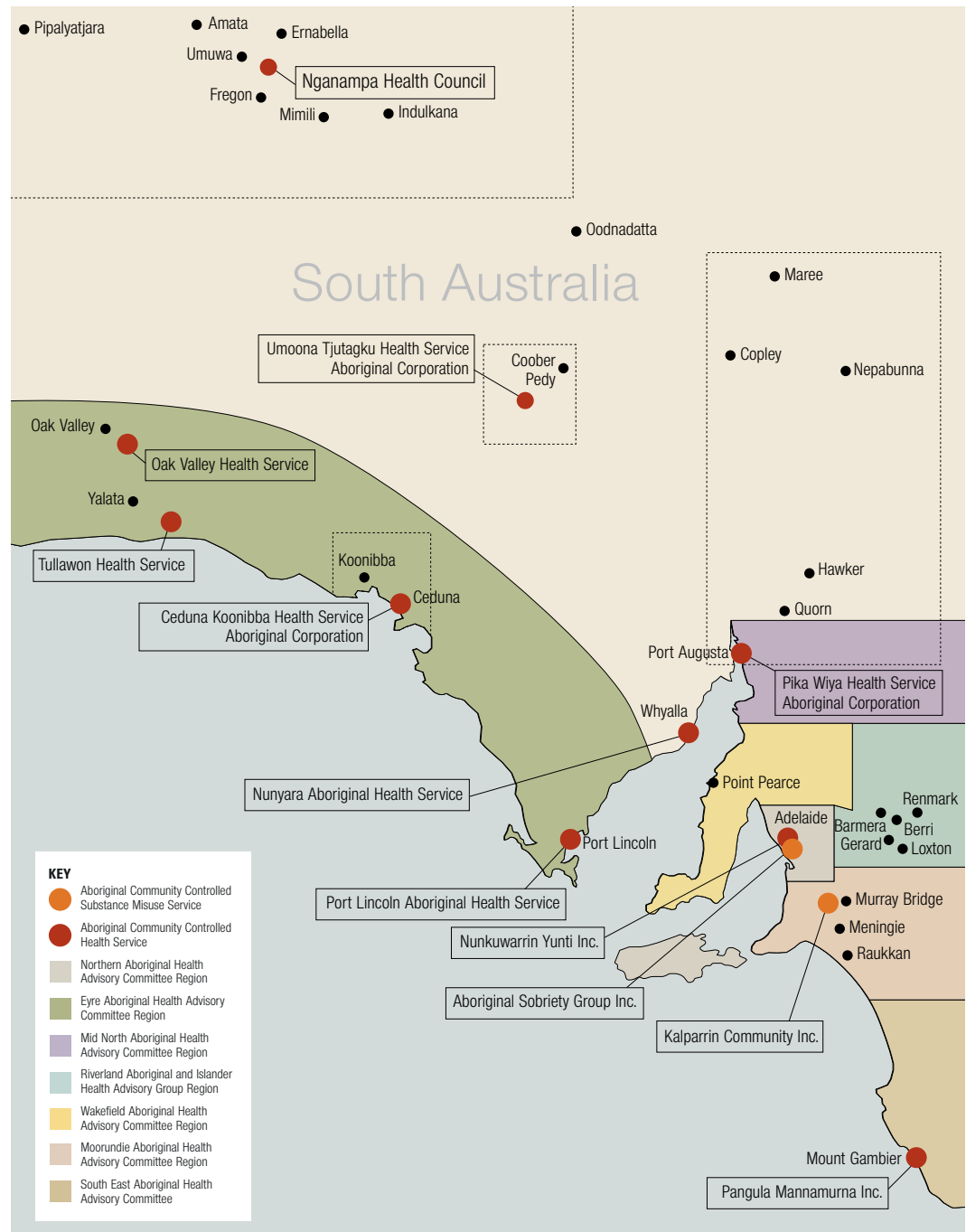
health sector and inter-sectoral accountability; ACCHO health service accessibility and quality, including early intervention, prevention and post-operative care; quality healthcare from an Aboriginal perspective; sustainable funding models for Aboriginal Health Workers, ACCHO services and programs; culturally appropriate and effective models of care; program monitoring, evaluation and inter-sectoral collaboration on knowledge translation; and Aboriginal workforce development with a priority on attracting young Aboriginal people to work either in the ACCHO sector or broader health sector; increasing the number of male Aboriginal health workers, Aboriginal registered nurses and other Aboriginal health professionals.

Finally, research is needed into increasing Aboriginal participation in the policy setting, enhancing the government's understanding of unique ACCHO healthcare service issues in some regions; Commonwealth, State and Territory Governments' accountability frameworks; cultural safety within mainstream services and increasing the flexibility of mainstream services to meet the needs of Aboriginal people.



Appendices

Appendix one: Map of South Australia ACCHOs and AHACS⁶



⁶ 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.



Appendix two: Aboriginal Health Research Ethics Committee objectives

AHREC was formed in May 1986. It was the first Aboriginal Human Research Ethics Committee in Australia. AHREC is mandated by National Health and Medical Research Council (NHMRC), whose main roles are to advise, develop and monitor research ethics and to fund research.

The objectives of AHREC are:

- To monitor and coordinate medical and health research in South Australia Aboriginal communities
- To offer advice to communities on the ethics, methodology and potential benefits of research
- To review the research needs of Aboriginal communities to determine research priorities.

For additional information see:
<http://ahcsa.org.au/research-overview/ahrec/>

Appendix three: Terms of Reference for the Co-investigators' Group

AHCSA is undertaking a process of research and consultation to seek consensus about research priority areas within the Aboriginal Community Controlled Health Organisations (ACCHOs), Aboriginal Health Advisory Councils (AHACs) and Country Health South Australia in South Australia.

This research follows on from a scoping study, 'Indigenous Health Research Scoping Study: Final Report' (AHCSA, 2005) commissioned by AHCSA to report on issues related to Aboriginal health research in South Australia. From the scoping study consultations, two priorities were identified for improving Aboriginal health research. The first was addressing the

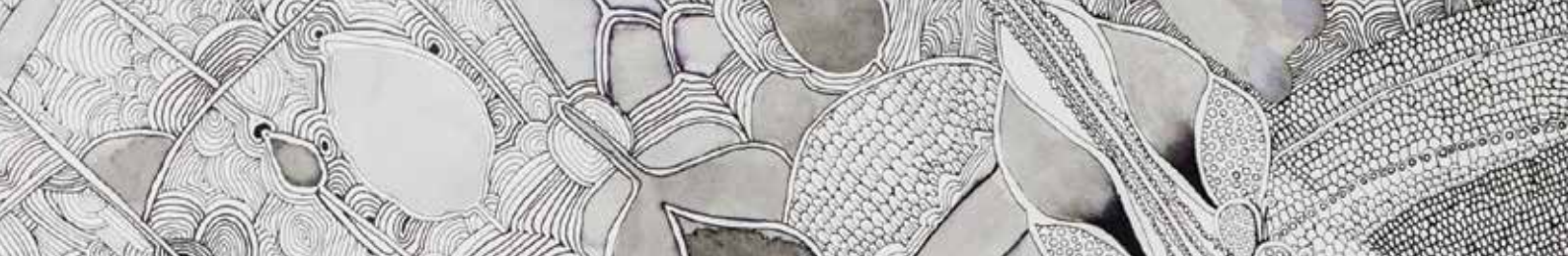
fragmented state of Aboriginal health research. The second was research and evaluation on health interventions and programs. Participants wanted a priority for research with an action and intervention orientation that had direct application to policy and health service delivery decisions (AHCSA, 2005, p 62). Other aspects of this priority were a need for multi-sectorial approaches and consideration of the social determinants of health. Furthermore, research needed to consider a wellness factor and find out what helps to keep people well and a specific effort for the translation of research into policy (AHCSA, 2005, p 63).

The findings from this study support the need to undertake more focused consultations to define current health research priority areas. Furthermore, it is now possible to include an audit of the Aboriginal Health Research Ethics Committee (AHREC) database to inform the ACCHOs, AHACs and others about the main areas covered by approved research from 2003 to 2012.

The work is a collaborative project between AHCSA and the Indigenous Theme within the South Australia Health and Medical Research Institute (SAHMRI). In the interests of capacity building and ensuring that the research is driven and overseen by a strong co-investigators' group with a majority of Aboriginal people, a team of co-investigators will have both oversight of the research and contribute practically to the research process including data analysis and review.

Role of the Co-investigators' Group

The role of the Co-investigators' Group is to steer this project; provide advice to the investigators (and others) throughout the project, including participant recruitment, data collection, data analysis, dissemination of the results and promote the aims and objectives of the project. The Co-investigators' Group is responsible for advising Next Steps on issues impacting upon health and wellbeing research in Aboriginal communities in South Australia.



Appendices

Specifically, the responsibilities will be:

- Participate in meetings of the Co-investigators' Group and contribute to all discussions related to the project.
- Review and comment on documents, drafts, reports and communication regarding the project.
- Assist with design of aspects of the methodology.
- Assist with data collection activities (if required), including attendance at workshops (if required).
- Positively promote the project within local networks and encourage participation in interviews, surveys and workshops by Aboriginal people and their organisations.
- Assist with the interpretation of results.
- Approve the Final Report.
- Assist with preparation of reports and/or publications arising from the research, including co-authoring articles.
- Declare any anticipated conflicts of interest.

Membership and composition

- Members of the Co-investigators' Group will be invited to become a Co-investigator by the project leaders for the Next Steps for Aboriginal Health Research: Exploring how research can improve the health and wellbeing of Aboriginal people in South Australia (Next Steps).
- The Co-investigators' Group is comprised mainly of Aboriginal people in the sector as well as academic and practice experts in a range of relevant areas (including Aboriginal health, Aboriginal Community Controlled Health Organisations, Aboriginal Health Advisory Committees etc.).
- Members will be appointed by SAHMRI and AHCSA for a term of one year or until completion of the project.

- The Co-investigators' Group may invite individuals who are not current members to participate in meetings in order to advise and provide relevant information to the project.
- Members will advise the Next Steps Research Officer/Assistant about meeting attendance.

Term of office

The project is expected to operate from November 2012 to November 2013.

Time commitment

There will be Co-investigators' Group meetings at least once per month. Other attendances at data collection, workshops, readings and reviewing are additional and dependent on the level of involvement the person wishes to, or is able to, have. The minimum commitment will be 2-3 hours a month.

Administration

- Professor Alex Brown (SAHMRI) and Dr Rosie King (AHCSA) will support the Co-investigators' Group.
- SAHMRI and AHCSA will provide secretarial support and out of pocket expenses will be reimbursed by the project.
- SAHMRI and AHCSA will provide verbal and written reports to the Co-investigators' Group on the progress and outcomes of Next Steps.
- A Next Steps Research Officer/Assistant (based at AHCSA) will provide the minutes and administrative assistance with setting up and scheduling meetings.
- Meetings will be conducted at a minimum of six times per year. Some out-of-session activity and input may be sought from time to time, including attendance at workshops, reading and reviewing, which are additional and dependent on the level of involvement the person wishes to, or is able to, have. The minimum commitment will be 2-3 hours per month.
- The appointment to the Co-investigator Group is honorary.



Appendix four: Participants

The following ACCHOs, including substance misuse services and AHACs participated in Next Steps:

- Port Lincoln Aboriginal Health Service Inc.
- Aboriginal Sobriety Group
- Ceduna Koonibba Aboriginal Health Service
- Nganampa Health Council
- Nunkuwarrin Yunti of South Australia Inc.
- Nunyara Aboriginal Health Service
- Pangula Mannamurna Inc.
- Pika Wiya Health Service
- Tullawon Health Service Inc.
- Umoona Tjutagku Health Service
- Mid-North Aboriginal Health Advisory Committee
- South East Aboriginal Health Advisory Committee
- Northern Aboriginal Health Advisory Committee
- Eyre Aboriginal Health Advisory Committee
- Moorundie Aboriginal Health Advisory Committee
- Wakefield Aboriginal Health Advisory Committee
- Riverland Aboriginal and Islander Health Advisory Group

Appendix five: Audit of the AHREC database

A detailed audit of the AHREC database was completed in March 2014. It included 212 files of approved research proposals dated February 2010 to February 2014. In-depth analysis was undertaken to ascertain answers to the following questions addressed by the audit:

1. What was the primary focus of the research?
2. Where was the research located?
3. How much research was undertaken with an ACCHO?
4. How much research was multi-sited (located in South Australia and other states or territories within Australia)?
5. Who were the participants in the research?
6. What was the level of governance indicated in the research?
7. How much consultation was undertaken in the research?
8. What indication of Aboriginal capacity building was in the research?
9. What types of research methods were used?

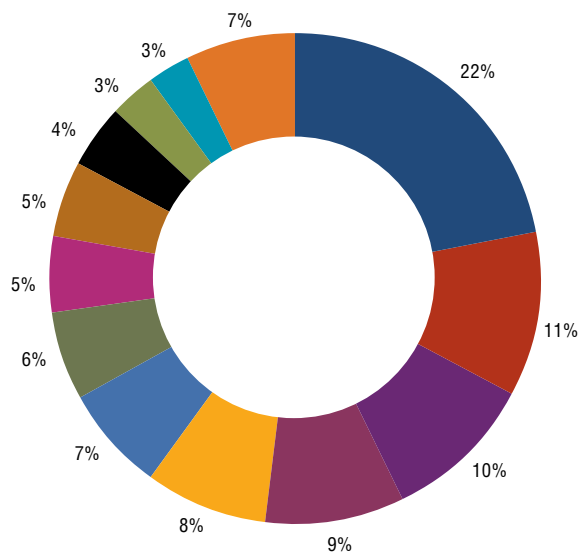
The findings in this document will centre on the primary focus of the research; the location of the research; the extent of research undertaken with an ACCHO; the participants in the research; the levels of governance indicated; consultation undertaken; Aboriginal capacity building and the types of research methods used.

1. What was the primary focus of the research?

Among the wide range of health topics covered by proposals, 52% of the 212 studies in the audit were focused on health services research (22% or 47 studies), general health (11% or 23 studies), chronic disease (10% or 22 studies) and social determinants of health (9% or 19 studies). The remaining 48% of possible research topics was spread among nine different topics areas, including alcohol and other drugs (N=18); social and emotional wellbeing (N=14); health promotion (N=13); health prevention (N=11); population health survey (N=10); nutrition (N=8) and other (N=15). Notably, mental health and obstetrics and gynaecology had the fewest number of studies, at 3% or 6 studies each.

Appendices

1. What was the primary focus of the research?



| PRIMARY FOCUS | No IN TRIAL (N) |
|--------------------------------|-----------------|
| Health service research | 47 |
| General health | 23 |
| Chronic disease | 22 |
| Social determinants of health | 19 |
| Alcohol and other drugs (AOD) | 18 |
| Social and emotional wellbeing | 14 |
| Health promotion | 13 |
| Health prevention | 11 |
| Population health survey | 10 |
| Nutrition | 8 |
| Mental health | 6 |
| Obstetrics and gynaecology | 6 |
| Other | 15 |
| TOTAL | 212 |

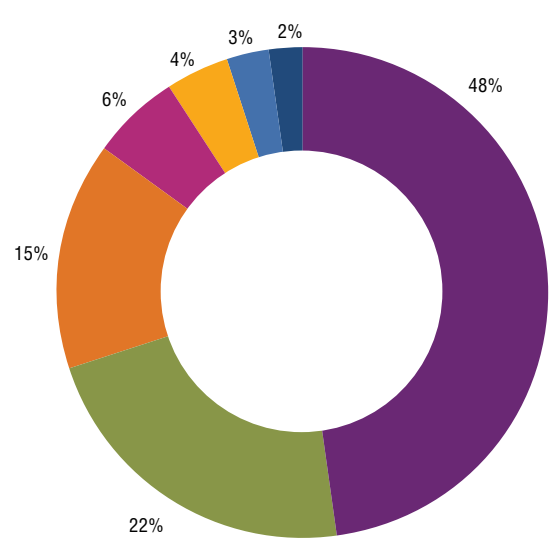
Of interest in this chart are the majority of studies that were focused on health services research, general health and chronic disease. Sub-topics within health service research included health service delivery (N=19); monitoring and evaluation (N=8) and access to services (N=4). Included under the general health topics were the sub-topics of birth (N=4); culture (N=4), and oral health (N=2). Chronic disease included sub-topics of cancer (N=5) and cardiovascular health (N=5).

The table below provides a breakdown of 'Other' (7%) from the pie chart, left.

| PRIMARY FOCUS - OTHER (7%) | No OF APPLICATIONS |
|----------------------------|--------------------|
| Acute disease | 1 |
| Communicable disease | 3 |
| Disability | 1 |
| Medicine/medication | 3 |
| Multi-morbidity | 2 |
| Research practice | 4 |
| Suicide | 1 |
| TOTAL | 15 |



2. Where was the research located?



In this question, multiple answers could be reported. Of the 212 research projects, 52 were national projects, 87 were located across South Australia and 73 involved parts of South Australia. It is interesting to note here that 48% of the studies were located in metropolitan Adelaide, 22% in the northern region of South Australia, 15% were in the Eyre region. Importantly, no studies undertaken during this four-year period were solely located in the Riverland; however, this area may have been included in projects involving the whole of South Australia or national projects.

| LOCATION | NUMBER OF APPLICATIONS |
|------------------------|------------------------|
| All of South Australia | 100 |
| Part of State | 112 |
| TOTAL | 212 |

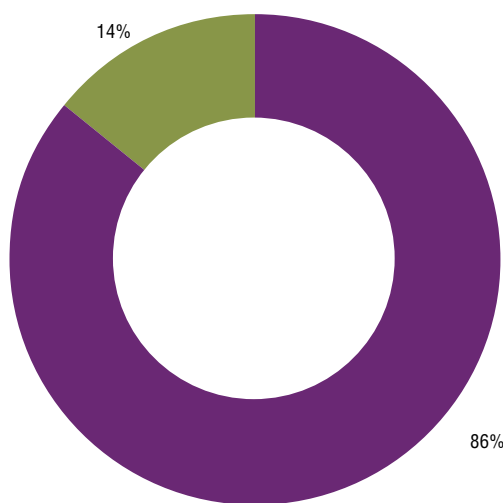
| | |
|--|----|
| Metropolitan Adelaide | 55 |
| Northern (APY Lands, Oodnadatta Marree, Port Augusta, Whyalla, Coober Pedy, Copley, Nepabunna) | 25 |
| Eyre (Oak Valley, Ceduna, Yalata, Koonibba, Port Lincoln) | 17 |
| Moorundie (Murray Bridge, Meningie, Raukkan, Adelaide Hills, Mount Barker, Southern Fleurieu) | 7 |
| Mid North (Port Pirie, Peterborough, Clare) | 5 |
| Wakefield (Point Pearce, Maitland) | 3 |
| South East (Mount Gambier) | 2 |
| Riverland (Renmark, Berri, Gerrard, Loxton, Barmera) | 0 |

3. How much research was multi-sited (that is, located in South Australia as well as other states or territories within Australia)?

| MULTI-SITED RESEARCH | No OF APPLICATIONS |
|----------------------|--------------------|
| Yes | 52 |
| No | 160 |
| TOTAL | 212 |

Appendices

4. How much research was undertaken with an ACCHO?

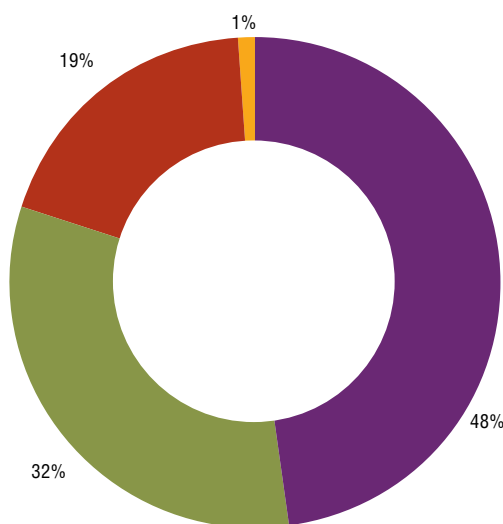


| | No IN TRIAL (N) |
|-----------------|-----------------|
| Yes, with ACCHO | 29 |
| No | 183 |
| TOTAL | 212 |

This pie graph provides a breakdown of how many research projects were conducted with an ACCHO. As there were only 14% of studies that were conducted with an ACCHO, this begs the question:

How can health research that does not involve the Aboriginal community controlled sector benefit Aboriginal people and their communities?

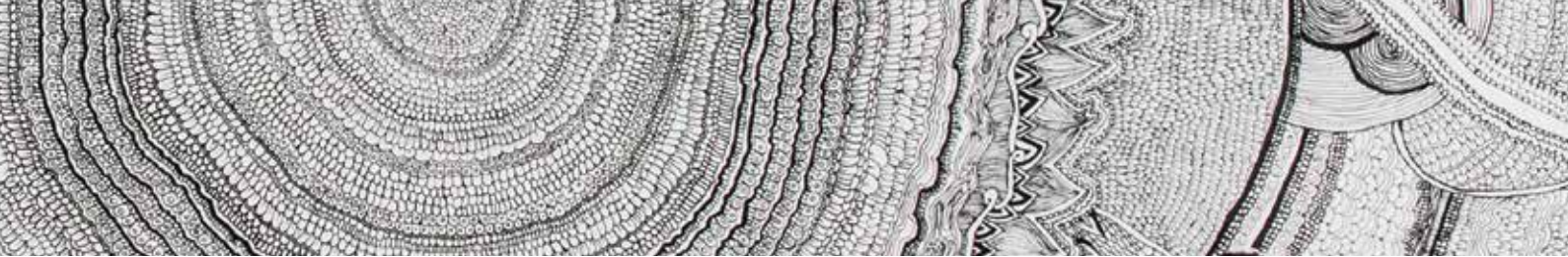
5. Who were the participants in the research?



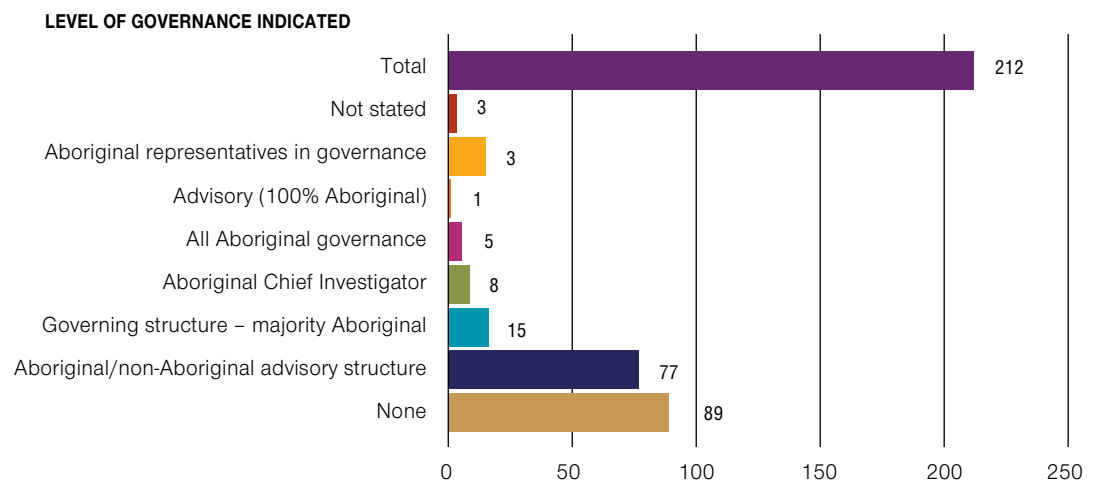
| PARTICIPANTS IN RESEARCH | No IN TRIAL (N) |
|---------------------------------------|-----------------|
| Aboriginal and Torres Strait Islander | 133 |
| General Australian population | 88 |
| Health provider | 52 |
| Not Stated | 2 |

| PARTICIPANTS IN RESEARCH | No OF APPLICATIONS |
|--|--------------------|
| Aboriginal | 70 |
| Torres Strait Islander | 0 |
| Aboriginal and Torres Strait Islander | 63 |
| General Australian population | 88 |
| Health provider (clinician, manager, administrator, ancillary staff) | 52 |
| Not stated | 2 |

In this question, multiple answers could be reported. Almost 63% (N=133) of studies stated the participants were both Aboriginal and Torres Strait Islander. No studies indicated the participants were Torres Strait Islander. Studies involving the general Australian population formed 41% (N=88), whereas 24% (N=52) of studies included health providers, such as clinicians, managers, administrators or ancillary staff.



6. What was the level of governance indicated in the research?

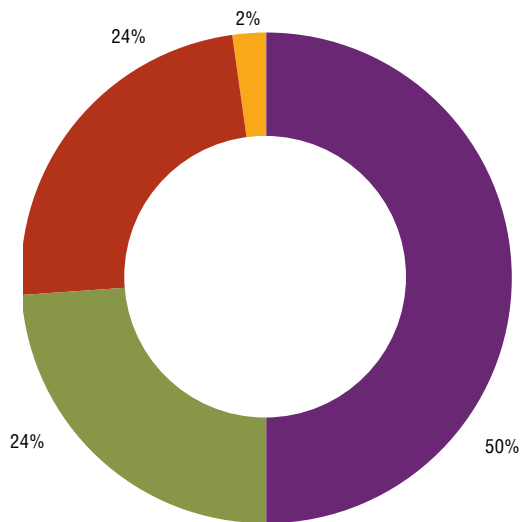


In this audit, governance structures were defined by how the study was managed and conducted. The advisory structure was defined by the ability to provide advice on aspects of the study, including cultural advice or on methodology. However, researchers could then use their discretion whether to use this advice or not.

Aboriginal people's involvement in the governance of research projects was most strongly represented in advisory structures (36%) and in governance arrangements (7%). However, 42% (N=89) of research projects had no Aboriginal people involved in the overall management or advisory structure. This figure includes projects conducted on the general population, which included Aboriginal and Torres Strait Islander people, where the question about governance was not asked.

Appendices

7. How much consultation was undertaken in the research?



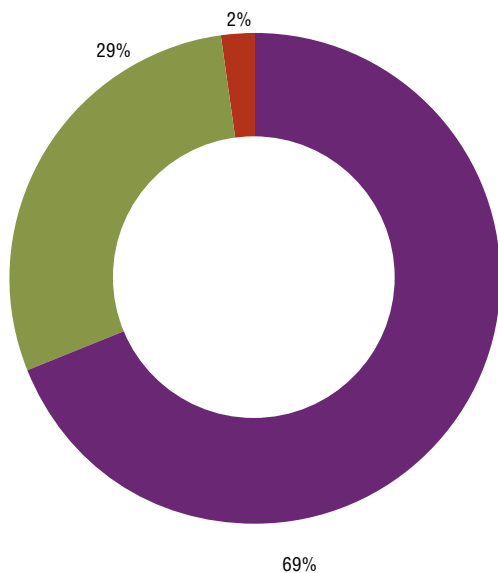
APPLICANTS IN RESEARCH

| | |
|------------|-----|
| Regular | 105 |
| Once only | 51 |
| None | 52 |
| Not stated | 4 |

TOTAL 212

This pie graph shows the level of consultation identified from 212 AHREC approved studies over a four-year period. While 50% of researchers consulted with Aboriginal communities and services, there were 48% that indicated consultation as being 'once only' or 'none'. It is worthwhile noting the practices of the recent past here, whereby AHREC approval could be provided, even when minimal or no consultation had occurred.

8. What indication of Aboriginal capacity building was in the research?

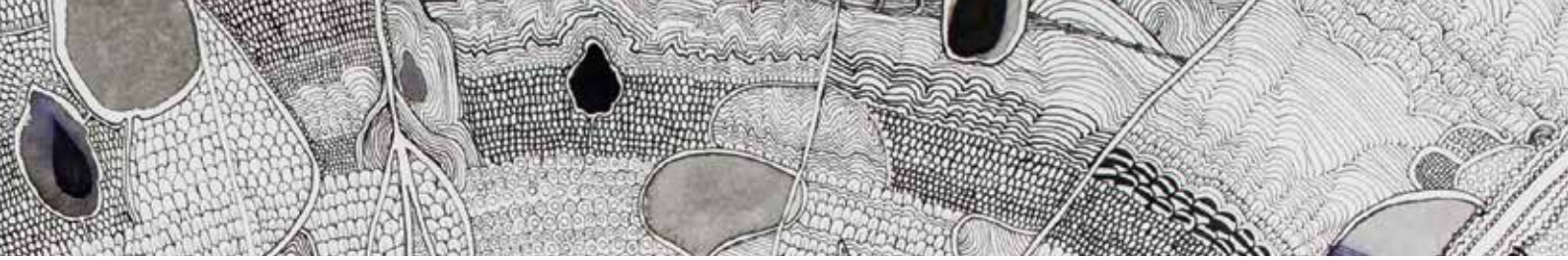


APPLICANTS IN RESEARCH

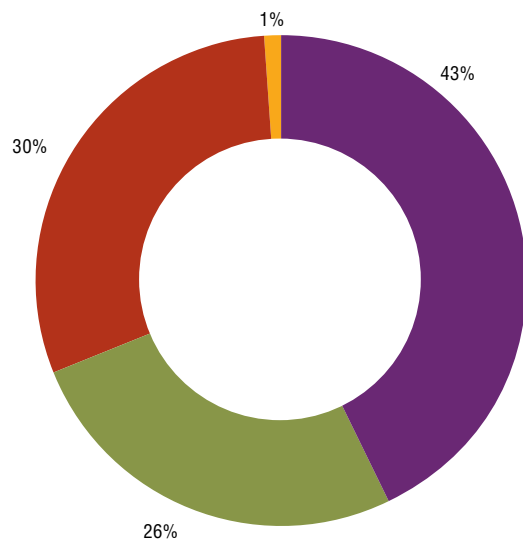
| | |
|------------|-----|
| Yes | 147 |
| No | 62 |
| Not stated | 3 |

TOTAL 212

From 2011, a new AHREC proposal form was introduced, which included questions about consideration of Aboriginal capacity building in research. Over this period, nearly one third (29%) of studies indicated consideration of, or inclusion of Aboriginal capacity building in the study. However, the results of this audit do not exclude general population studies looking at historical medical records in a hospital setting. Notwithstanding this, 69% (N=147) of studies indicating no Aboriginal capacity building is a significant figure in this context.



9. What types of research methods were used?



APPLICANTS IN RESEARCH

| | |
|---------------|------------|
| Mixed methods | 91 |
| Qualitative | 56 |
| Quantitative | 64 |
| Not stated | 1 |
| TOTAL | 212 |

Appendices

Appendix 6: Agenda for the Consensus Workshop

Venue – The Rockford Hotel, 164 Hindley Street, Adelaide South Australia 5000

| DAY ONE: 1 APRIL 2014 | | |
|------------------------------|--|--|
| 12.00 pm | Lunch | |
| 12.30 pm | Welcome to Country | Karl Telfer |
| 12.45 pm | Introductions | Kim O'Donnell |
| 1.00 pm | PRESENTATIONS Background: - How the project came about | Mary Buckskin, Prof Alex Brown and Dr Rosie King |
| | What is research and the role of SAHMRI's Wardliparringa Unit in this study | Prof Alex Brown |
| | How was it done? (Methodology) | Janet Stajic |
| | Findings – Audit of AHREC approved research projects | Kim Morey |
| | Findings – Interviews with AHCSA members and stakeholders | Dr Carol Davy |
| | - What are the current issues of concern? - What should research focus on in the future? | Kim Morey and Janet Stajic |
| 2.30 pm | RESPONSE TO THE PRESENTATIONS | Mary Buckskin and Prof Alex Brown |
| | Questions and Discussion | All |
| 3.00 pm | Afternoon Tea | |
| 3.30 pm | GROUP DISCUSSIONS - Do you agree with the high level themes that have been identified? - What does this mean for your local region? - What issues are important? - What may be missing? | Facilitated by Kim O'Donnell |
| 5.00 pm | Close Day One | Kim O'Donnell |
| 6.00 pm | Workshop Dinner | The Rockford Hotel |
| DAY TWO: 2 APRIL 2014 | | |
| 9.00 am | WELCOME AND PLAN FOR DAY TWO | Kim O'Donnell |
| 9.15 am | Group Discussions – review of Day One | Facilitated by Kim O'Donnell |
| 9.45 am | Plenary – Feedback from each group discussions | |
| 11.00 am | Morning Tea | |
| 11.30 am | Findings – Interviews with AHCSA members and stakeholders | |
| | How should research be conducted? | Dr Rosie King and Anna Dowling |
| | Wardliparringa Proposed 'Accord' and how it aligns with the findings from the Next Steps Research Project | Kim Morey |
| 12.00 pm | Plenary Discussion – Agreed Outcomes for the Workshop | |
| | CLOSING REMARKS | Kim O'Donnell, Mary Buckskin and Prof Alex Brown |
| 1.00 pm | Close Day Two | Kim O'Donnell |
| | Lunch | |



Appendix 7: Additional Resources

National Aboriginal Community Controlled Health Organisation's definition of health

Aboriginal health means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing about the total well-being of their Community' (NACCHO, 2006).

Australian Human Research Ethics Guidelines

Produced by the National Health and Medical Research Council (Australian Government)

'National Statement on Ethical Conduct in Human Research' (2007) Updated March 2014

'Values & Ethics: Guidelines for Ethical Conduct in Aboriginal & Torres Strait Islander Health Research' (2003)

'Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics' (2006) and 'Road Map II' (2010).

Australian Medical Services Alliance Northern Territory (AMSANT): Aboriginal Health Research Policy

AMSANT have developed a Research Policy which includes a research analysis template to assist people thinking about requesting AMSANT input into their projects. Both the Research Policy and the research analysis template can be found by following the link: <http://www.amsant.org.au/index.php/resources/research>

Closing the Gap Clearinghouse, Australian Institute of Family Studies

Osborne K, Baum F & Brown L (2013) *What works? A review of actions addressing the social and economic determinants of Indigenous health.* Issues paper no. 7. Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies.

Wise S. (2013) *Improving the early life outcomes of Indigenous children: implementing early childhood development at the local level.* Issues paper no. 6. Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies.

Australian Institute of Health and Welfare

<http://www.aihw.gov.au/>

AIHW, 2014. *Timing impact assessment for COAG Closing the Gap targets: child mortality*, Cat. No. IHW 124, Canberra, AIHW.

Lowitja Institute

Australia's National Institute for Aboriginal and Torres Strait Islander Health Research
<http://www.lowitja.org.au/>

EthicsHub

An online resource to support people and organisations working or participating in Aboriginal and Torres Strait Islander Health Research <http://www.lowitja.org.au/ethics>



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Carson B., Dunbar T., Chenhall R. D. and Bailie R. (2007) *Social determinants of Indigenous health*, Crows Nest: New South Wales, Allen and Unwin.

National Aboriginal Community Controlled Health Organisation (NACCHO) History, <http://www.naccho.org.au/about-us/naccho-history/#intro> Accessed 14.08.2014)

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