

Aboriginal Health Research Ethics Committee
AHREC Celebrating 30 Years



Aboriginal Health Council
of South Australia Inc.



Aboriginal Health Research
Ethics Committee
of South Australia

our health, our choice, our way



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Acknowledgements

The Aboriginal Health Council of South Australia Inc. (AHCSA) would like to express its sincere gratitude to AHREC Chairpersons, members and Executive Officers for their role since 1986 in the advancement of Aboriginal health through ethical code of conduct in research.

In collaboration with AHCSA’s member services and through the efforts of Community members and specialists in medicine, research and law, we are confident that AHREC will continue to serve as a protection for our Community and promote culturally appropriate research design and implementation.

AHREC Celebrating 30 Years

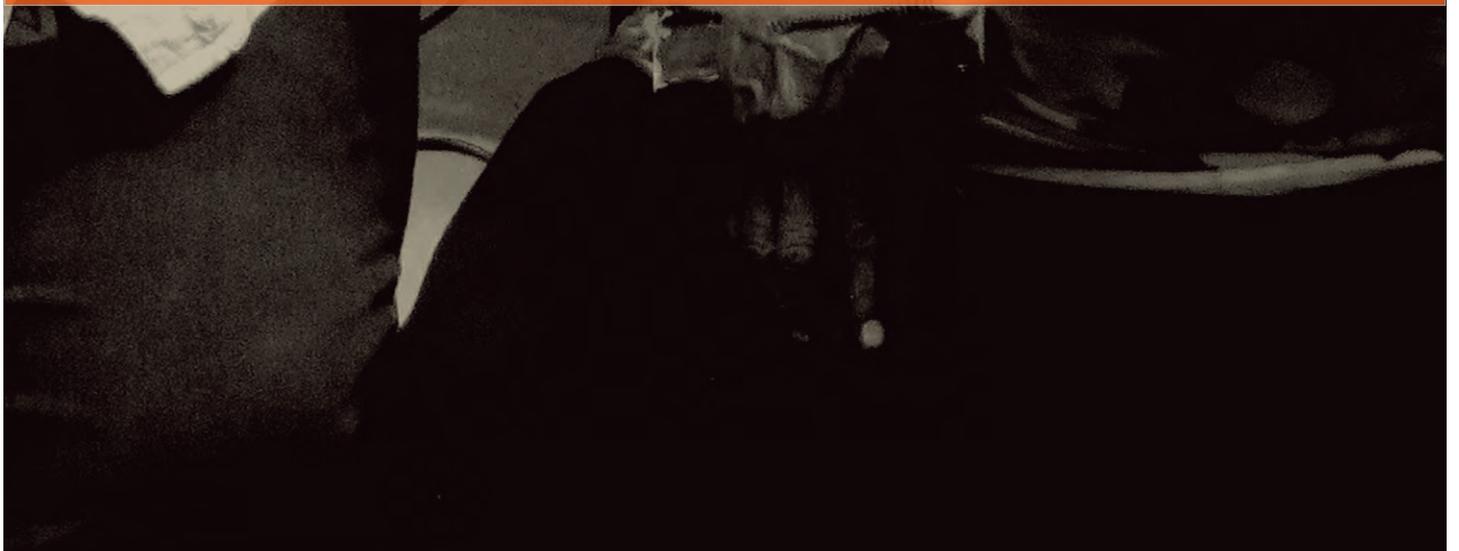
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AHREC ensures ethical code
of conduct in research through
collaboration with communities



Foreword

Shane Mohor, Chief Executive Officer
Aboriginal Health Council of South Australia Inc.

The Aboriginal Health Research Ethics Committee (AHREC) was established 30 years ago due to our community's concerns about research being unchecked. It has been serving our community since. I am pleased to mark AHREC's milestone and note that through the efforts of our community, Member services and the selfless contributions of many, we now have set criteria through which only those researchers who prove their cultural competence and methodological rigour pass.

Over the past 30 years, AHREC has also proved to be an institution of goodwill that bridges the gaps in researchers' understanding of our Community and Member services in South Australia. AHREC is mandated by our constitution and is an ethics committee registered with the National Health and Medical Research Council (NHMRC).

This means that AHREC is a speciality-based institution that does not only provide cultural expertise from our point of view but also reviews studies with expert insights and knowledge from various perspectives involving specialists from medical, research and legal fields.

AHREC's 30th milestone marks the history of our people having a nationally recognised, expert institution through which we can refuse to be subject to scientific curiosity and unenlightened perspectives. This is an era where we can identify who we wish to work with, how, and, most importantly, on our own terms, according to our priorities.

This is an era where we can advocate for and improve the health and wellbeing of our people through avenues of partnership, negotiation, collaboration and dialogue. Now it is the responsibility of those who wish to talk with us to prove their cultural competence in accordance with the values of our community and justify their actions that will not harm the physical, social and emotional wellbeing of our people.

AHREC is a gateway to reviewing all types of scientific studies from all levels of researchers – from students to professors. Regardless of titles, their intentions and methods are closely scrutinised by our specialists on the Committee.

The key benefits of institutions such as AHREC, as a sub-Committee of AHCSA, may not always be visible due to their confidential proceedings that prevent harm from occurring in the first place. AHCSA ensures through sub-Committees such as AHREC, that we will continue to promote our cultural values, and where required, prevent inappropriate ideas from perpetuating the mistakes of the past amongst our Community.

At the very heart of every ethical review, the wellbeing of an Aboriginal person is at stake and I would like to thank AHREC Chairpersons, Members and Executive Officers since 1986 who have developed and relayed this message to researchers. I would also like to thank our Member services for their support and involvement in research and evaluation activities that have been recommended for consideration by AHREC.

RESPECT



Respect This symbol represents a path leading to the peak of a ridge or hillside. Aboriginal people use these paths as vantage points to view or observe the landscape from a higher point of view, respectfully taking the whole picture into consideration.

Vision

As a sub-committee of the Aboriginal Health Council of South Australia Inc. (AHCSA), the Aboriginal Health Research Committee (AHREC) is a registered Human Research Ethics Committee with the National Health and Medical Research Council

Our mission, as guided by the Aboriginal Health Council's constitution, is to promote and ensure the ethical conduct of all research initiatives in partnership with Aboriginal organisations, communities and people. We aim to achieve this by maximising the capacity of the Aboriginal community in determining their health and wellbeing through community participation and ownership.

AHREC contributes to AHCSA's vision as the advocate serving to protect the Community by supporting ethical and rigorous research design, implementation and knowledge translation.

AHREC is a sub-Committee with outcomes that contribute towards all of AHCSA's constitutional objectives to:

1. Operate as the peak body for Aboriginal health in South Australia.
2. Improve the health outcomes for all Aboriginal people of South Australia, promoting and advancing the community's commitment to physical, social and emotional wellbeing and quality of life.
3. Build the capacity of members to create a strong and enduring Aboriginal Community Controlled health sector and contribute to improving the capacity of mainstream health services to respond appropriately to the health needs of the Aboriginal community of South Australia.
4. Contribute to the development of a well-qualified and trained Aboriginal health sector workforce.

SUSTAINABILITY



Sustainability Water and fresh water springs represent the flow of life, renewal and how water sustains life in cycles spanning generations.



Innovation This symbol represents a tree root growing under the ground, and finding its way around obstacles on its journey, creating new paths as it grows bigger and stronger.

AHREC's Purpose and Requirements

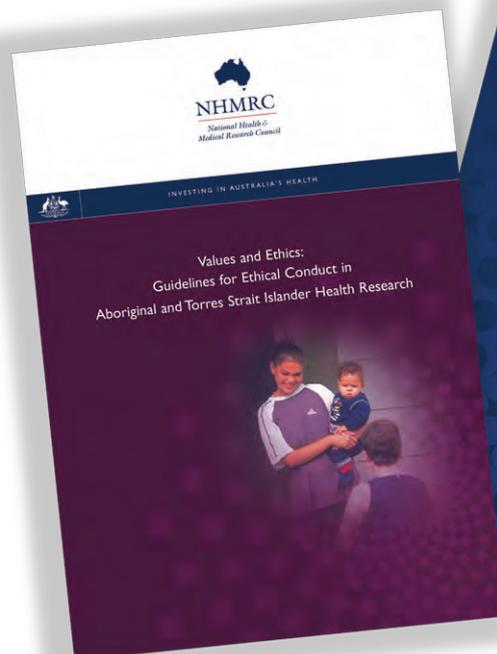
AHREC is committed to and endorses the National Aboriginal Community Controlled Health Organisation (NACCHO) definition of Aboriginal health and primary health care, where:

'Aboriginal health means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing about the total wellbeing of their Community. It is a whole of life view and includes the cyclical concept of life-death-life'.

AHREC is guided by the AHCSA Constitution and operates in accordance with the NHMRC National Statement on Ethical Conduct in Human Research and other relevant federal and state legislation and regulations.

The Committee reviews studies also with respect to the:

- Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (2003)
- Australian Code for the Responsible Conduct of Research (2007)
- NHMRC Guidelines under section 95 and section 95A of the Privacy Act 1988



AHREC's Purpose and Requirements



In addition to these guidelines, AHREC also conducts reviews with particular consideration for other companion documents and collaborative publications including:

- Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics (2005)
- South Australian Aboriginal Health Research Accord Companion Document (2014)
- Next Steps for Aboriginal Health Research Final Report (2015)

AHREC's deliberations take into account AHCSA's priorities and commitment to develop and assess culturally appropriate methods of research for the benefit of the South Australian Aboriginal Community. All research submitted to AHREC must place the needs, priorities and wellbeing of the South Australian Aboriginal Community before the needs of the study and present a partnership approach at all phases with a feasible knowledge translation strategy involving relevant Aboriginal organisations.

All research submitted to AHREC must meet with good research practice and present a rigorous methodology in terms of quantitative representativeness and qualitative data saturation. The methodology should be designed to adequately answer the study's research questions and achieve meaningful research outcomes for the South Australian Aboriginal Community.

If an application does not meet the requisite research and ethical standards (i.e. inadequate sample size, community consultation, governance structure, lack

of understanding of research methods, inability to articulate or respond to the Committee's concerns), it is at AHREC's discretion to not further review the study, advise its re-submission at least three months after the initial review or progression without the Aboriginal component.

In order to ensure that student applicants are properly and adequately supervised, and, the students' wellbeing is protected, the Committee requires supervisors of all students wishing to conduct research in the Aboriginal health sector to thoroughly assess the feasibility of achieving the scope with respect to the student's timeframes, capabilities and academic level. All applicants, regardless of their academic or professional level, must be aware of the ethical and research standards they need to meet.

If the Committee assesses that a submission by a student is sub-standard and under or inadequately-supervised (e.g. there is a significant room for improvement in all aspects of the application), it may refer the student to their research office and/or the Head of School for support ahead of any further correspondence with the Committee. The values¹ that lie at the heart of these guidelines are:

Spirit and Integrity	Equality
Respect	Survival and Protection
Reciprocity	Responsibility

¹For further information with regards to how these values should be demonstrated, please access: *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*, NHMRC.

AHREC's Scope of Review

AHREC reviews studies that are directly related to health and wellbeing of Aboriginal people. Health and wellbeing are defined as per the National Aboriginal Community Controlled Health Organisation's (NACCHO) definition.

The researchers are required to seek AHREC's approval based on the following:

- The primary research goals and questions of study are directly related to health research and wellbeing; and
- The experience of Aboriginal and/or Torres Strait Islander people (hereafter referred to as Aboriginal) is an explicit focus of all or part of the research; or
- Data collection is explicitly directed at Aboriginal people; or
- It is proposed to conduct sub-group analysis and separately analyse Aboriginal people in the results; or
- The information, potential over-representation in the dataset or geographic location has an impact on one or more Aboriginal communities;
- Aboriginal health funds are a source of funding;
- If it is a review of governmental services with impact on the Aboriginal Community or organisations and there is an intention to disseminate key findings or recommendations in a public report.

The researchers are required to acquire other appropriate approvals at an organisational or university level or from the relevant governmental departments:

- If the study is not directly related to health;
- If it is a mainstream study and its proposed references to Aboriginal people are only in terms of demographics at the total sample level with no sub-group analysis; or
- If the proposed study does not hold research characteristics (e.g. no hypotheses) and is an evaluation of project/program outcomes. For example, KPI reporting of an Aboriginal organisation for project management purposes or continuous quality improvement activities with no intention to publish in peer-reviewed journals;
- If it is a scoping review of publicly available information/services or systematic literature review.

Whether a study requires ethical review by AHREC or not is reviewed on a case-by-case basis depending on study parameters, purpose and activities. Whilst such study types may be out of AHREC's scope of review, Aboriginal involvement on the interpretation of findings and knowledge translation activities such as community reports, forums or conversations with key Aboriginal stakeholders is strongly recommended for all studies.

FOSSILS

Fossils Aboriginal artefacts that are found buried beneath the surface of our land and sea speak to our ancestral past and influence our present and future.

Celebrating 30 Years

Kim Morey, Chairperson
Aboriginal Health Research Ethics Committee

AHREC is guided by the AHCSA Constitution and operates in accordance with the NHMRC National Statement on Ethical Conduct in Human Research and other relevant federal and state legislation and regulations. The Committee also reviews studies with respect to Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, the Australian Code for the Responsible Conduct of Research (2007) and the South Australian Aboriginal Health Research Accord Companion Document (2014).

AHREC's deliberations take into account AHCSA's priorities and commitment to develop and assess culturally appropriate methods of research for the benefit of the South Australian Aboriginal Community.

Each year, AHREC receives an increased number of research ethics proposals, from research specifically relating to our communities or those studies where Aboriginal people will be impacted by the research.

AHREC, through the support of AHCSA, have provided advice and endorsement to the Accord, developed by SAHMRI's Wardliparingga Unit in collaboration with AHCSA, the Council of Elders and the three South Australian Universities, to improve how research is conducted with South Australian Aboriginal communities and Community Controlled Health Services.

The Accord was signed and committed to by AHCSA, the Council of Elders South Australia, SAHMRI, and the three South Australian universities on the 2nd of September 2014.

Whilst the Accord was being developed in 2013, the first partnership with AHCSA and Wardliparingga commenced, with the Next Steps for Aboriginal Health Research Final Report (2015). This project aimed at identifying and prioritising the main health and medical research areas that align with the needs and interests of Aboriginal people within the ACCHO sector, the Aboriginal Health Advisory Committees and the broader Aboriginal community in South Australia.

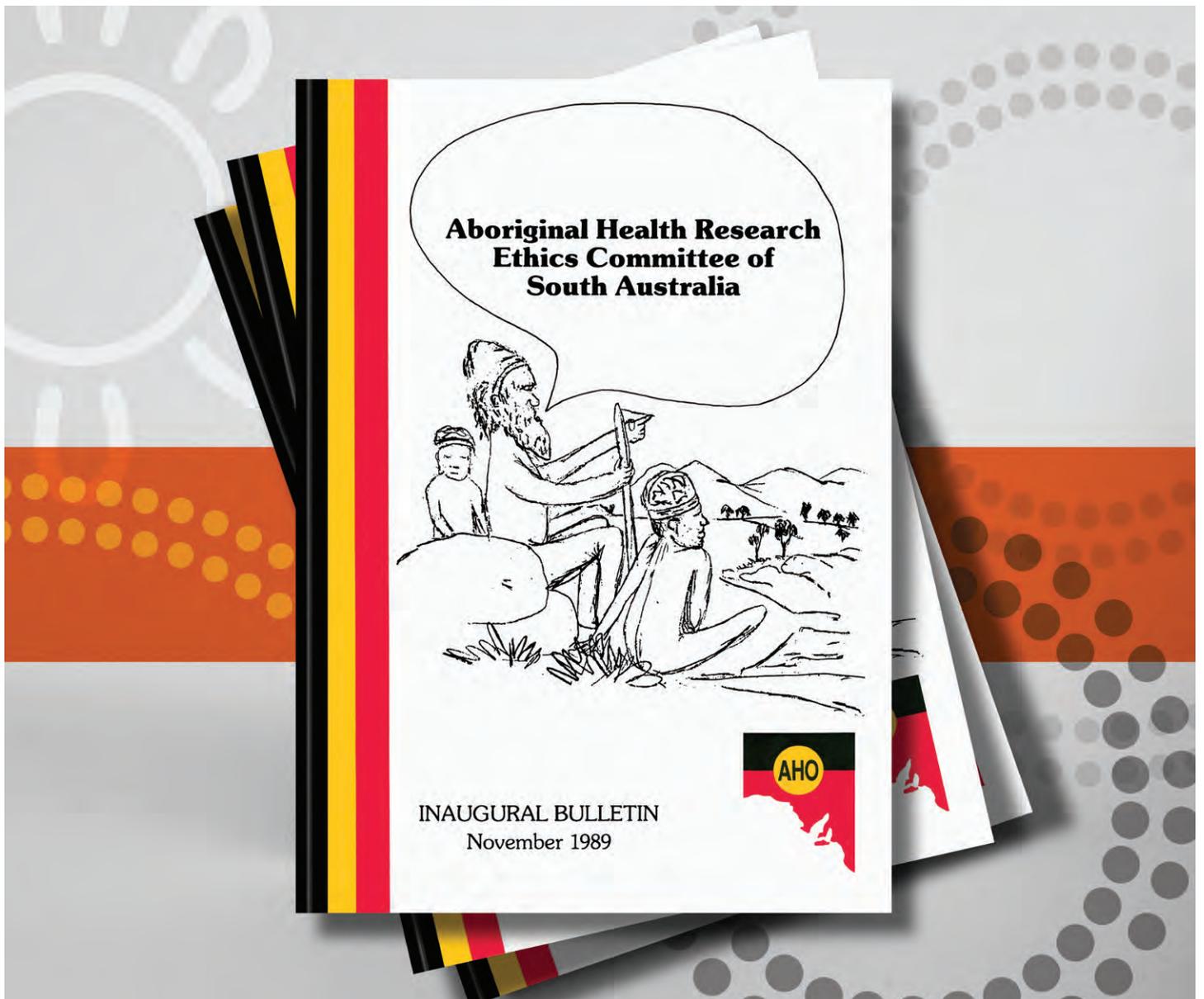
Furthermore, Next Steps conducted a retrospective audit of research proposals approved by AHREC over a four year period between 2010 and 2014. These two pieces of foundational work, have assisted AHREC to ensure that research being proposed within South Australia meets with the priorities of the community, that the research is supported by our member services, that there is control over the research process, data and outcomes, and that ultimately, the research will provide a meaningful benefit to our people.

AHREC have refined it's 'terms of reference' and have aligned the AHREC's code of conduct with that of AHCSA. We have commenced and continue to build relationships with Human Research Ethics

CULTURE



Culture This is the centre of Aboriginal being - it is our home, our comfort and our shelter. This symbol represents that shelter and the cultural collective of Aboriginal community groups across South Australia.



Committees (HRECs) operating within SA Health hospitals and will aim to engage with the university HRECs in building our relationships, as well as promoting the scope of AHREC's terms of reference, so as to ensure that high quality Aboriginal review of research proposals that have the potential to impact on our people is undertaken.

AHREC, through its rigorous review and high-level scrutiny of research proposals, contributes to improvements in the quality and standards of research being proposed and conducted within Aboriginal health. AHREC has a strong focus on ensuring that not only is the research a priority for Aboriginal communities, but that the research must have a benefit to the Aboriginal community, and will in fact bring about meaningful change through knowledge translation activities.

AHREC strongly believes that research conducted the 'right way' plays a very important and significant role in building the evidence required within Aboriginal health, and in turn has the potential to improve health service delivery, policy, programs, hospital care and sustainability of

Aboriginal programs. Improvements in these key areas are likely to increase the quality of life of Aboriginal people and improve the overall health outcomes for our people, families and communities.

AHREC strongly believes that research conducted the 'right way' plays a very important and significant role in building the evidence required within Aboriginal health

The Past and the Journey

Alwin Chong, Executive Officer (2001-2011)
Aboriginal Health Research Ethics Committee

When I was appointed as the Senior Research and Ethics Officer with the newly reincorporated organisation, the Aboriginal Health Council of South Australia Inc. (AHCSA) in 2001, I quickly became aware of several significant events that occurred in South Australia, in 1986, 1991 and 2001, with regards to Aboriginal health.

In 2001, AHCSA was reincorporated, allowing the organisation to become independent of the Government and function as a community controlled organisation. The Aboriginal Health Research Ethics Committee (AHREC) was established in 1986. This saw it become the peak State Aboriginal health ethics committee of South Australia. In 1991, the National Health and Medical Research Council (NHMRC) introduced ethical guidelines to provide guidance to researchers and Human Research Ethics Committees (HREC's) around researching Aboriginal communities.

Change over from Aboriginal Health Organisation to AHCSA

AHCSA began its life in 1981 as an incorporated health unit under the South Australian Health Commission Act, and was known as the Aboriginal Health Organisation (AHO). The Board of Management was elected by the government. AHO was located at 62 Beulah Road in Norwood, before moving to the Aboriginal Health Division for a number of years and then to independent premises at 167-168 Fullarton Road, Unley in 1995-1996.²

The Report of the Committee of Review into Aboriginal Health in South Australia (1984) – the Foley Report, was the first of many. It recommended the

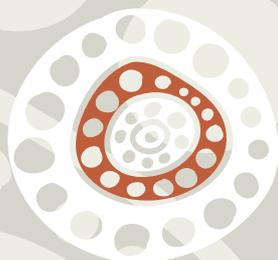
establishment of the Aboriginal Health Council of South Australia Inc. as a statutory body. The Council was to be a community controlled process 'independent of Government influences and interference'. The primary roles of the Council would be to coordinate, research, inform, educate and train. Aboriginal health services continued to be funded by the Commonwealth, while Aboriginal Hospital Liaison Officers were established and funded by the State.³

Although many important issues flowed from the Foley Report, the late 1980s was a time of change and uncertainty, with other reports and recommendations from different groups. There was little action between 1988 to 1990 with another major review of AHO and the advent of the National Aboriginal Health Strategy (NAHS) in 1989.⁴

Another review, A Strategy Assessment of the Aboriginal Health Organisation and Advisory Mechanisms for Aboriginal Health Matters in South Australia (1988) – the Sayers/O'Donoghue Report, recommended creating a formal advisory mechanism for working with Aboriginal people and that the AHO not be a service delivery organisation.

In December 1990, AHCSA was established with the majority of funding still coming from the Commonwealth. The organisation continued to be incorporated under the Health Commission Act but had a policy and advisory role as the Sayers/O'Donoghue Report recommended. This reflected the principle of Aboriginal self-determination that was also emphasised in the NAHS. However, there were growing concerns about the independence of the organisation while being tied in some way to the government structure.⁵

INCLUSIVENESS



Inclusiveness This symbol represents the coming together of health professionals, providing collaborative opportunities for people to learn about Aboriginal health issues.

The Past and the Journey

The Cooley Report, another review of AHCSA, was announced and completed in 2000. It recommended that AHCSA be reincorporated under the Associations Incorporation Act, South Australia 1985. The Report talked about really becoming independent and strengthening that advisory role, as a separate organisation and no longer being incorporated under the Health Commission Act, although it would continue to receive both State and Commonwealth Government funding. In October 2001, AHCSA became a community controlled organisation governed by a Board of Directors whose Members represented Aboriginal Community Controlled Health and Substance Misuse Services and Aboriginal Health Advisory Committees (AHACs) throughout South Australia.

Aboriginal Health Research Ethics Committee

Equally as important as the reincorporation of AHCSA was the establishment of the Aboriginal Health Research Ethics Committee (AHREC). AHREC was established in 1986 following concerns by the then Aboriginal Health Organisation of South Australia about the increasing volume of research being conducted in Aboriginal communities in South Australia. This process was strongly supported by the Chairman of the Medical Research Ethics Committee, National Health and Medical Council, Professor Ross Kalucy.⁶

The original committee consisted of:

Margaret Hampton

Chairperson, Medical Research Ethics Committee
Director, AHO

Professor Ian Maddocks

Professor of Palliative Care, Flinders Medical Centre

Ceilia Divakaran-Brown

Health Researcher, AHO

Dr Brian Hobbs

Community Health Coordinator, AHO

Dr Peter Lake

Community Physician

Jenny Baker

Nursing Sister, Aboriginal Medical Service

Muriel Van der Byl

Eminent Community Representative

David Branson

Eminent Community Representative

Andrew Collett

Barrister and Solicitor

Fr Mark Nugent

Minister of Religion

One of the major discussion points about AHREC in this early period was always about how it could become a truly statewide representative committee. However, the financial impracticalities associated with travel for potential members outside the metropolitan region were substantial. There was never any requirement under the NHMRC for a mandated ethics committee to be representative but this discussion was more about fitting in line with the principles of Aboriginal community control.

In these early days, when the ethics committee was based in the Aboriginal Health Organisation, the committee was originally managed by Ceilia Divakaran-Brown and Graham Brice prior to me taking over this role. Initially, the role of the Ethics Officer was to work under direct supervision of Aboriginal elders and leaders to re-establish and develop AHREC with multi-faceted cross-cultural expertise as well as 'vet' research proposals designed to investigate Aboriginal communities.⁸

This position matured and developed further into a much broader role than envisaged. This included providing an educational role, working closely with researchers and education institutions in order to ensure researchers were well equipped to conduct research studies in Aboriginal communities.

Another significant event during this period was the introduction of the Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research (1991) by the National Health and Medical Research Council (NHMRC).

Professor Ross Kalucy, the Chairman of the Medical Research Ethics Committee of the National Health and Medical Research Council (NHMRC) had strongly supported the need to expand the existing NHMRC ethics guidelines to give due consideration to how sensitive research is in Aboriginal health. A working party, set up by the NHMRC, comprising of NHMRC members and Aboriginal representatives had already commenced this task at the time of the AHREC being established.

The guidelines were specifically developed to provide guidance to researchers and Human Research Ethics Committees (HRECs) on the complex considerations necessary in the conception, design and conduct of appropriate research in Aboriginal and Torres Strait Islander communities. The guidelines have changed over time to reflect the changing nature of research in Aboriginal communities, but the importance of ensuring sound ethical practices in conducting research studies in Aboriginal communities is still relevant today.

²Aboriginal Health Council of South Australia. AHCSA News ³Aboriginal Health Council of South Australia. AHCSA News ⁴Buckskin, Mary; Keeler, Ngara; Stacey, Kathleen.

⁵Buckskin, Mary; Keeler, Ngara; Stacey, Kathleen. ⁶Aboriginal Health Organisation. Aboriginal Health Research Ethics Committee of South Australia ⁷Aboriginal Health Organisation. Aboriginal Health Research Ethics Committee of South Australia. ⁸Aboriginal Health Organisation. Aboriginal Health Research Ethics Committee of South Australia.

The Past and the Journey

In 2003, the Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (Values and Ethics) was developed by an Australian Health Ethics Working Committee, which replaced the Guidelines on ethical matters in Aboriginal and Torres Strait Islander Health Research (1991). There is currently a review of the Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research being conducted by the NHMRC.⁹

The concerns that were raised by Aboriginal communities and health service providers about the increasing volume of research being conducted in Aboriginal communities in South Australia was equally about the ethical review process as it was about Aboriginal communities being active partners in the research process.

Challenges for AHREC

In the early period, many researchers were not aware of AHREC or that there was a new set of NHMRC ethical guidelines for engaging Aboriginal communities – often, the response was that they had acquired ethical approval from their institution or organisation and had met the ethical obligations to continue their research study. This highlighted two issues that included:

1. Researchers now having to submit an ethics application to AHREC for consideration, if their research involved Aboriginal participants; and
2. Researchers understanding that the Guidelines on ethical matters in Aboriginal and Torres Strait Islander Health Research (1991) was specifically about understanding and acknowledging the complex considerations necessary in the conception, design and conduct of appropriate research in Aboriginal communities.

When informed that they were required to submit and acquire ethical approval from AHREC, as well as their institution or organisation, this often created some anger or bewilderment about what was so different between the two ethics committees. Some researchers also protested about time being wasted, which put their funding at risk. In many of these cases, researchers had won the research grant but not recruited an Aboriginal community in which to conduct the research.

This highlighted the practice that existed prior to AHREC being established, which included researchers winning research grants then attempting to find an Aboriginal community where they could conduct their research study. This perpetuated the practice of Aboriginal people being subjects and not partners in the research project. An integral

part of this practice was researchers arguing that the cost of engaging Aboriginal communities in the developmental stages of their research funding grant, especially in rural and remote regions, was too high, especially given that there was no guarantee that they would be successful in winning the grant.

The above practices emanated out of the past where many anthropologists would travel to Aboriginal communities, take notes from their informants and then head back to their institution to transcribe, analyse and write up their research findings. The analysis of the data, often included an interpretation of information that was collected from Aboriginal informants – the tyranny of distance and the limited communication tools meant that it was impractical to speak with the informants about this information – this often meant that a non-Aboriginal person would interpret the Aboriginal content, which was based on a different worldview.

Over time, this practice became entrenched in academia due to Ethics Committees reviewing proposals for their methodologies rather than Aboriginal engagement or the recognition of cultural elements, the analysis of the data was in isolation of any Aboriginal input, publications were peer reviewed by non-Aboriginal academics or professionals, authorship excluded Aboriginal involvement and the citing of these publications reinforced the position of these researchers as experts in Aboriginal cultures.

Reviewing the methodologies of research projects is important but so is the question of how researchers engage with Aboriginal communities to participate at all levels of the research project.

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⁹National Health & Medical Research Council. 2015.

The Past and the Journey

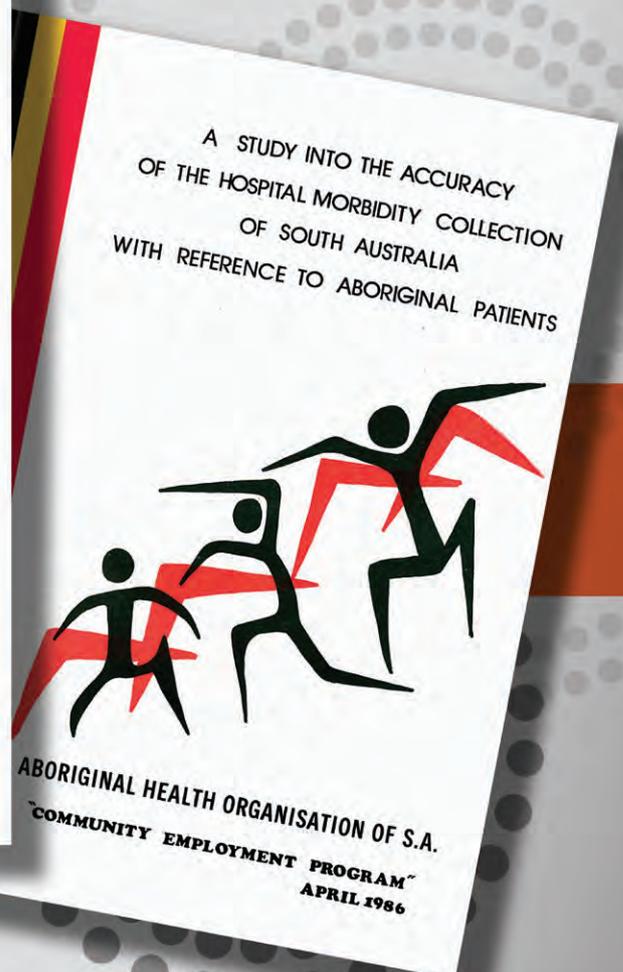
This process became accepted as 'normal' practice in research. However, as the numbers of Aboriginal academics began to increase in the 1970s and 80s, there was much more analysis and criticism of this infrastructure, especially around the exclusion of Aboriginal involvement as partners, the ownership of data and the peer review process. Aboriginal academics are still required to comply with this process today, but there are many more Aboriginal researchers, academics and professionals who are invited to peer review publications.

An important rider must be added here about anthropologists being the first academic scholars to research Aboriginal cultures and they did this with good intentions and a genuine concern about Aboriginal cultures being lost to Australia and the world. Since the 1980s, many Aboriginal people who

were part of the Stolen Generations, have begun using these publications as their initial starting point in trying to find their cultural heritage.¹⁰

This highlighted that although AHREC was established primarily about the lack of control over the increasing volume of research being conducted in Aboriginal communities in South Australia, there was still a need for rigorous research evidence in Aboriginal health to inform policy makers. However, the research needed to be conducted in an appropriate manner that allowed Aboriginal communities to drive the agenda, be active partners in the research and acquire some benefits that would have a positive impact on their health.

¹⁰Cowlinshaw, Gillian. Friend or foe? Anthropology's encounter with Aborigines. Inside Story.



The Past and the Journey

This procedure was equally about an ethical review process that was inclusive of Aboriginal communities in the research study as it was about the need for rigorous research evidence in Aboriginal health.

Other challenges included:

- AHREC members becoming fully acquainted with and knowledgeable about the Guidelines on ethical matters in Aboriginal and Torres Strait Islander Health Research as these were the guiding principles that the ethics committee used as the platform for reviewing ethics proposals. This also involved researchers, research institutes and organisations understanding what the new Guidelines represented in terms of being aware of the complex considerations necessary in the conception, design and conduct of research in Aboriginal communities.
- Some researchers, believing that the process of submitting and acquiring ethical approval from AHREC was too hard, would deliberately exclude Aboriginal issues from their project, other than in a very broad population breakdown. In these cases, the research project would not be specifically Aboriginal but included a cohort that could have been used to make comparisons between Aboriginal and non-Aboriginal populations about health issues – this could have informed or raised questions for future research studies.
- The regular NHMRC training and upskilling of members was a challenge for AHCSA as the NHMRC did not provide funding or support for Ethics Officers. As a small organisation, that relied on Government funding, AHCSA could not support Members to attend training courses. Members often had to pay for the training themselves, which was not the fault of AHCSA but highlighted a much bigger problem of funding in Aboriginal health.
- Promoting AHREC to researchers, research institutions and organisations, Aboriginal communities and other ethics committees became increasingly important. Especially when researchers would explain that they did not know about AHREC, even after they had applied for and obtained ethical approval from their host institution. The essential solution to this challenge was to have a positive working relationship with the ethics committees from educational institutes in South Australia. This meant that over time, it became essential criteria for researchers to obtain ethical approval from AHREC, if the project involved Aboriginal people, as well as from their host institution.

Some of the achievements:

- A better professional relationship with other HRECs in South Australia meant that researchers, who had not been aware of or submitted their ethics application to AHREC, would be notified about the obligation to submit and obtain ethical approval from this committee, if the research project involved Aboriginal people. This relationship was reinforced by the commitment of the HRECs not to approve applications until AHREC had done so.
- In addition, there is a much broader understanding of AHREC and its role and responsibilities by researchers, research and education institutions and the health sector in general.
- More researchers are now approaching AHREC with intentions to develop research projects involving Aboriginal communities and are seeking advice about the process of doing so – there are also publications that can help researchers with the process but it's often about finding a suitable Aboriginal community prior to developing a research funding grant.
- Arguably, the biggest achievement has been the education of Aboriginal communities that are not only more aware of AHREC but generally have a better understanding of research and its importance – the monitoring of the research, once projects have commenced, is done by the community. Ensuring communities are fully informed and have a clear understanding of the project, is the first step to this monitoring process. AHREC is the body that ensures researchers have a clear communication strategy that can inform communities about their project as well as allowing the community to become monitors and they do this very well.

This procedure was equally about an ethical review process that was inclusive of Aboriginal communities in the research study as it was about the need for rigorous research evidence in Aboriginal health

Key Observations

Many Aboriginal communities have expressed the view that they are over-researched. This may be true in some communities, and they also believe that there has been limited impact from the research in their community. However, given the worsening health crisis in Aboriginal communities, there is still a need for rigorous research evidence to inform policy makers that can improve the health outcomes of Aboriginal people.

Furthermore, there is a serious need for more evaluations or systematic reviews of existing projects in Aboriginal communities that appear to be achieving their aims and objectives but have no way of assessing this other than through anecdotal evidence, which is not good enough. This is generally due to the lack of resources and priority by funding bodies who argue that evaluations are outside of their funding scope.

After 30 years, the presence of AHREC has become even more important than ever, due to the increasing health crisis affecting Aboriginal communities.

There has been an unwavering and steadfast commitment from members of the Aboriginal Health Research Ethics Committee during this period.

I would like to take this opportunity to thank all of those involved with the committee during my tenure as the Ethics Officer for allowing me the privilege of working with you.

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CASE STUDY

THE ABORIGINAL FAMILIES STUDY

What was the study about?

The Aboriginal Families Study is research about the experiences of Aboriginal women and families having a baby in South Australia. The aims of the study are to:

- Compare the experiences and views of women attending mainstream models of antenatal care with those accessing care via the Aboriginal Family Birthing Program
- Assess factors contributing to early and continuing engagement with antenatal care
- Use this information to inform strengthening of services for Aboriginal families.

Researchers at the Murdoch Childrens Research Institute and University of Adelaide in partnership conducted the study with the Aboriginal Health Council of South Australia Inc.

What was done

A team of 12 Aboriginal research interviewers invited women living in urban, regional and remote areas of South Australia to take part in the study by completing an interview booklet when their baby was around four to nine months old. Before the study started, a research partnership was formed with AHCSA and two Aboriginal researchers, Roxanne Miller and Hayley Wilson. They consulted with Aboriginal community organisations and communities to hear what they thought about the idea of a research project to discover what women having a baby in South Australia think about the care they received from services when they were pregnant, and after baby was born. An Aboriginal Advisory Group was established in 2007 to guide the study, and met regularly with the researchers to ensure that the study stayed on track.

Who took part?

344 women who had a baby in South Australia between July 2011 and June 2013 took part in the study. The average age of women in the study was 25 years; the youngest was 15 and the oldest was 43.39% of women were living in Adelaide at the time of completing the interview booklet, 61% were living in regional and 39% in remote areas of South Australia.

For more information including copies of the Policy Papers and Journal Articles please access: <https://www.mcrc.edu.au/research/projects/aboriginal-families-study>

Some Reflections on AHREC

Dr Peter Lake, Member – Aboriginal Health Research Ethics Committee

I first joined the Aboriginal Health Research Ethics Committee (AHREC) in 1989 while working for Adelaide Aboriginal Medical Service (AMS). The committee was then part of the Aboriginal Health Organisation (AHO), a unit of South Australia's Health Department. Later AHO, became separately incorporated and the Aboriginal Health Council of South Australia Inc. (AHCSA) was formed.

During the 1980s, around Australia there was considerable rivalry between State Government Aboriginal health units and Federally funded community controlled AMSs.

I was invited onto AHREC with the Adelaide AMS's Clinic Manager, Jenny Baker, to help bridge the gap between the two South Australian organisations. A year later, I left Adelaide AMS, began teaching Aboriginal Health Workers and coordinating curriculum development at AHO, but I stayed on the ethics committee because of my Aboriginal and public health experience. At the time, I was also researching prison health services for the Black Deaths in Custody Royal Commission.

I continued as a committee member of AHREC through subsequent jobs – with Port Adelaide Community Health, then Pangula (Mount Gambier), Tullawon (Yalata), and private practice. I am still an AHREC member.

In 1989, AHO occupied a big old building on Beulah Road, Norwood (now a private cardiovascular institute). Margaret Hampton, a senior Aboriginal health worker, was AHO Director and the late Brian Hobbs the organisation's medical officer. Brian was a GP with a background in overseas development

aid. Both were leading lights on the committee, as was Professor Ian Maddocks, a palliative care physician with long experience in Papua New Guinea.

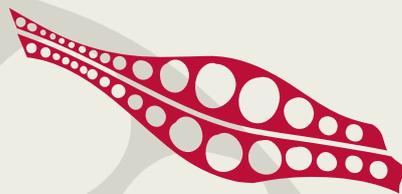
Unfortunately, records of early meetings have not survived the several moves and other organisational changes. However, my recollection is that the committee was much smaller than it is now. In those days, we were aware that a lot of research was going on in Aboriginal communities across South Australia, but for the first few years the committee was often bypassed.

Occasionally, this was intentional, but usually, researchers did not realise the committee existed. As time went on, AHREC grew in stature and authority and became affiliated with National Health and Medical Research Council. This imposed procedural and other requirements such as membership composition (e.g. lawyer, minister of religion or equivalent and so on). Since then, links have gradually been formed with funding bodies and mainstream health ethics committees.

It has now reached the desirable point where almost all health research involving Aboriginal people in South Australia cannot proceed without AHREC first reviewing the proposals and giving the go ahead.

Approval by AHREC was never a 'rubber stamp'. Common issues have related to confidentiality, ownership of data and lack of informed consent because of badly written participant information sheets. Perhaps more than mainstream committees, AHREC has taken the position that poor research methodology is unethical because it can lead to incorrect conclusions, waste resources and produce bad policy outcomes.

ACCOUNTABILITY



Accountability Two journey lines that are similar but not the same, represent Aboriginal elders who are responsible for teaching our young ones, and leading them on the right path. Their approach may not be the same, but their message is consistent.

Some Reflections on AHREC

Consequently, the wide variety of proposals coming before the committee (usually six or more new proposals per month) are carefully scrutinised with constructive suggestions fed back to applicants.

At times, the committee invites researchers to present in person. Occasionally assessment of very complicated proposals has required the help of outside experts – epidemiologists or those with specialised content skills related to the research topics. Serious flaws have been uncovered, even with multimillion dollar proposals. In some of these instances, projects would not have been practical due to researchers' lack of local knowledge or cultural awareness. AHREC community members have been invaluable in discovering these problems.

The committee has become adept at mediating between interests of the researchers on the one hand and requirements of Aboriginal communities on the other.

Since the 1980s there has been a move away from purely biomedical research initiated by non-Aboriginal university academics. These projects still appear but are now outnumbered by needs assessments and evaluations of existing programs.

Many of the proposals in recent years have been submitted by Aboriginal researchers responding to their community's requirements for high quality research. A very gratifying development.

Finally, the operation of the committee has changed beyond recognition since the 1980s. Now it is run as a tight ship by and for Aboriginal people, a number of whom are qualified researchers themselves.

Most health research for Aboriginal people in South Australia cannot proceed without AHREC first reviewing the proposals

CASE STUDY

THE OVERBURDEN REPORT

This report is an exemplary study that has been through AHREC's ethical review process. It is recognised by the Aboriginal community and the Aboriginal Community Controlled Health Organisations as a landmark initiative.

The study highlighted the challenges in funding structures that impact on the capacity of services and quality of care. The key findings of the study included:

- Fragmented funding is a barrier to integrated Primary Health Care.
- Unmanaged complexity and transaction costs cause inefficiency.
- Long-term relationship behaviour enables trust and enhances capacity.
- Data for monitoring and performance management are compromised.
- Current practice presents a paradox between classical and relational contract structures.

The study recommends the use of following principles to assess options for good practice in funding and regulation:

- Long-term contracting for core PHC is the basis for the funder-provider relationship.
- Core PHC funding allows flexibility for local priority setting, in accordance with agreed plans.
- Data collection and monitoring are simplified and information is shared, based on sound performance and health outcome indicators.
- Transaction costs are reduced and complexity is managed through a single, main, long-term contract and good contract management.
- Risks for both sides are managed and capacity on both sides is enhanced.

For more information please access:

<https://www.lowitja.org.au/lowitja-publishing/C026>

<https://www.lowitja.org.au/sites/default/files/docs/Overburden%20summary%20brochure.pdf>

Dwyer, J., O'Donnell, K., Lavoie, J., Marlina, U. & Sullivan, P. 2009, The Overburden Report: Contracting for Indigenous Health Services, Cooperative Research Centre for Aboriginal Health, Darwin.

On Values

Dr Gokhan Ayturk, AHREC Executive Officer
and AHCSA Senior Research and Ethics Officer

I have thought long and hard about what I shall write about this momentous note in history; whether it should be in my usual tick-all-boxes style or a philosophical deliberation about the temporal dimensions of ethics debating how all that is ethical now being potentially unethical tomorrow... I have had the privilege to listen to many stories from the Community and I hope that you will accept the story I wish to share – a personal story about values as it relates to the values I strive to relay and protect every single day.

The story begins with my nana when she was eight. Being the eldest in her family, she was taken out of primary school to look after her siblings as well as cousins. As a result, she has never learnt how to read and write though she has always been a whiz in math – somehow. At the age of 38, she became a widow with five children when my grandfather died in a car accident. She was able to keep the family together, with the help of my mother who was 16 at the time, the eldest of the five. As a result, I was fortunate to enjoy a childhood surrounded by my three uncles and an aunty in a family who had to figure out how to push through challenges together – with my nana as my primary carer during childhood.

Being originally from a land far away, I have been on what feels like a lifelong inter-continental walkabout since I left home at age 17. I have lived most of my life away from family, which enabled me to learn how to appreciate everything from a myriad of perspectives. I got married in Australia in 2012 and I knew that I had to take my wife and in-laws to Western Turkey for a local version of the wedding. This was to honour my nana and parents, and, for the induction of my wife and in-laws into the family.

Throughout my journeys my nana never told me anything too encouraging or discouraging; it's not possible to translate the true meaning of wise words spoken in the language of a high-context culture to a low-context culture but she used to say something like 'as you shall find out my child...' and 'as much as you can know about it at the time my child...' In September 2012, we were all enjoying a conversation that lasted for hours at the venue where the wedding was going to be held, and, my nana suddenly said 'OK, I have got something to say, I want you to tell everyone...'

This was a shock to the family knowing how she always keeps a calm and cool demeanour, and, extremely rarely interferes, confronts or makes a statement. She said, for the first time, something that translates roughly to:

'I have always been worried about my boy...I have always been worried since he left home...I didn't know where he was going...I didn't know how...I worry no more...Because, I now know that he is amongst people with good values...'

Her statement left my mother, aunty and mother-in-law in tears. Nana was referring to my wife and in-laws, and, did not care about who they were, how they looked, what they were doing, how they talked, how they sat down at the dinner table etc. – all she cared about was their values.

It was her single most significant criterion that provided her with the closure she needed; about me being far away from her about me being amongst people, circumstances and challenges that she could not really visualise. She knew that I was going to be

COLLABORATION



Collaboration A woven pattern found in traditional basket weaving represents working together for a strong, collective solution. The strands weave together, forming a robust, functional basket.



On Values

all right, one way or another; because she found that I was amongst people with good values.

She waited 20 years to relay this message about what truly matters in life and the only condition that elevated her concerns: values. Today, she has even fewer reasons to worry and is very proud to hear me tell her about the values of the Community I work with every day.

I am honoured to say that on the ethics front of my daily endeavours and at the heart of my role at AHREC are the following values: respect, reciprocity, equality, responsibility, protection, survival, spirit and integrity. In Aboriginal health, these are values that are inseparable from a cause – a cause of justice and self-determination.

Ethics and the role of AHREC is a valuable means to an end that may not be near. This is a collective journey that will continue to gravitate more strength, support and wisdom towards it from all directions and stakeholders. Even if the destination may not be near, it is hopefully on the horizon. It is through such building blocks that, one day in the future, we shall hope to see that these values will become the norm in practice and not only on paper. As an integral part of a much larger cause, these values must be embodied as meaningful and consistent actions in practice, where practice is adequately equipped and justly empowered to drive the policy.

Today, the Committee operationalises these values in line with its original purpose and the will of the Community. The Committee:

- **Paves the way to worthwhile, community oriented research** by providing materials and advice to researchers preparing research grant applications to prepare the way for worthwhile research conducted in an appropriate, ethical manner.
- **Advocates that poor science is bad ethics** by discussing and resolving ethical concerns from a range of Aboriginal and scientific perspectives in order to ensure that research carried out in South Australia with a significant Aboriginal client or population and health focus, operates from a sound methodological/ethical foundation.
- **Supports community control** by emphasising that AHREC's role is to recommend or not recommend proposed research to Aboriginal communities or key organisations. An important principle is that those communities or key organisations ultimately decide whether to welcome or reject proposed research.

Where required, AHREC requests researchers to go through the requisite consultation and engagement process, and, provide evidence of support from local communities and organisations.

- **Facilitates participation** by ensuring that all research tools such as consent forms, information sheets and methods are culturally appropriate and clear for the Aboriginal communities.
- **Tunes in to community needs** by building effective working relationships with Aboriginal communities and key organisations in order to be proactive in shaping research around needs identified by those communities or organisations, or issues that have been neglected.

As of 2016, because of the dedication, perseverance and wisdom of innumerable people and Elders past and present, we are at a point where, for example, some of the university-level ethics committees stipulate that if AHREC provides an approval to a study, researchers do not need to go through the university-level review process.

Looking forward, AHREC will continue to evolve and adapt, and will not only continue to deliver timely and fair ethical reviews in accordance with the National Statement and the other relevant guidelines; its functions will continue to extend to the protection and advocacy of values in pursuit of improved health and well-being of the Aboriginal communities in South Australia. During this process, the issues of interest that the Committee wishes to look into further include:

- Promoting the role of AHREC to other HRECs in South Australia.
- Understanding pathways of collaboration with Aboriginal-specific HRECs in other jurisdictions, especially with regards to studies with a national scope.
- Knowledge translation of research findings back to the Community.
- Articulating different types of studies in Aboriginal health and assessing the feasibility of low or negligible risk application pathways.

Next Steps Recommendations

As part of this milestone, we also would like to acknowledge the findings of the Next Steps study, which aimed to identify and prioritise the main health and medical research areas that align with the needs and interests of Aboriginal people within the ACCHOs, the then Aboriginal Health Advisory Committees (AHACs) and the Aboriginal community in South Australia.

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

The key recommendations arising from the study for researchers included:

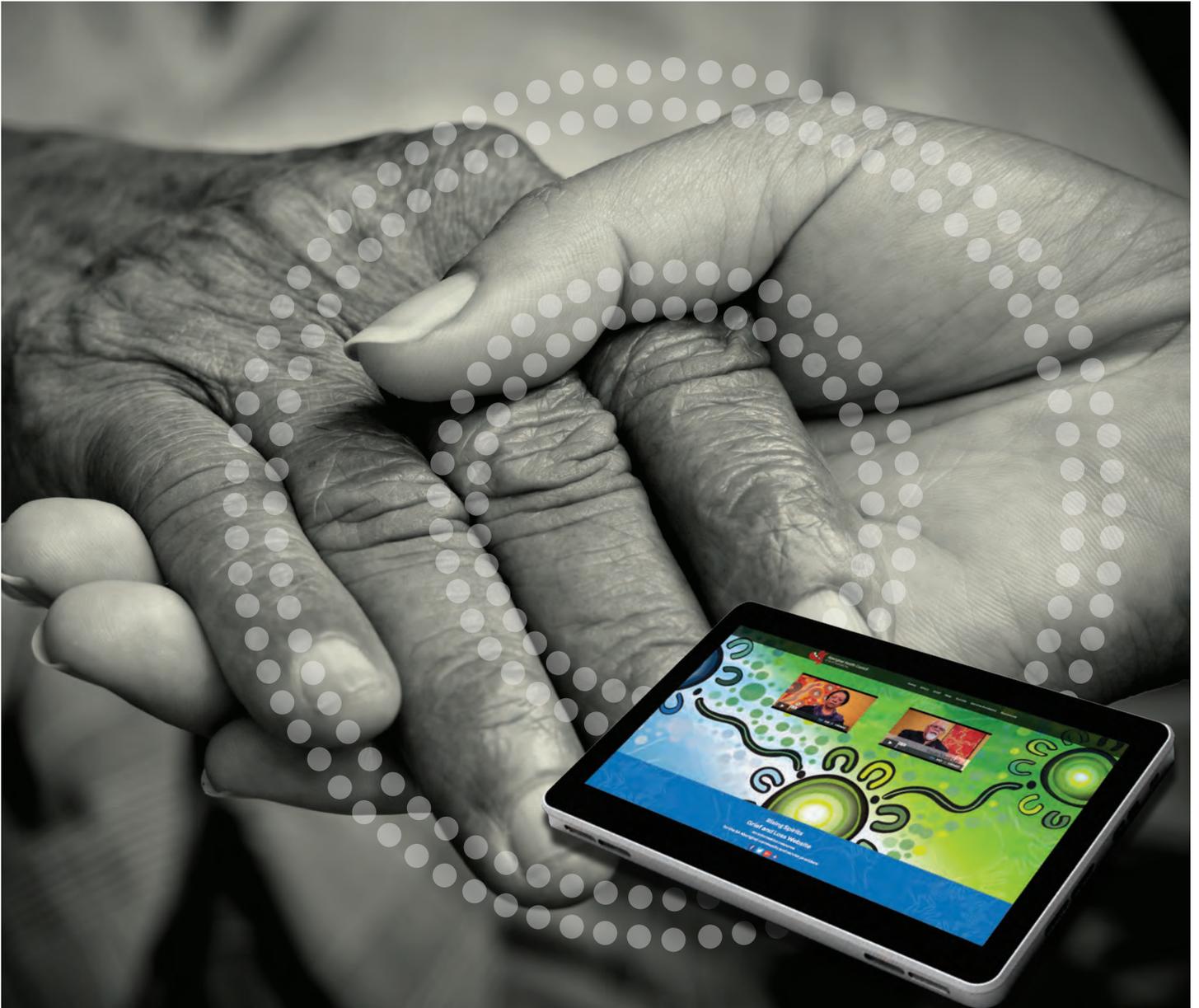
- To respect the authority of ACCHOs and to do their homework on the organisation, Aboriginal population and local area.
 - Find out about cultural protocols and follow them.
 - Seek guidance from an Aboriginal cultural mentor.
 - Be prepared to drop their own (or industry) agenda(s) and consult with 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.

Other general recommendations included:

- 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.

SUPPORT

Support This symbol represents gathering sites; places where advice is offered to communities and researchers on the ethics, methodology and the benefits of culturally sensitive research within Aboriginal communities.



CASE STUDY

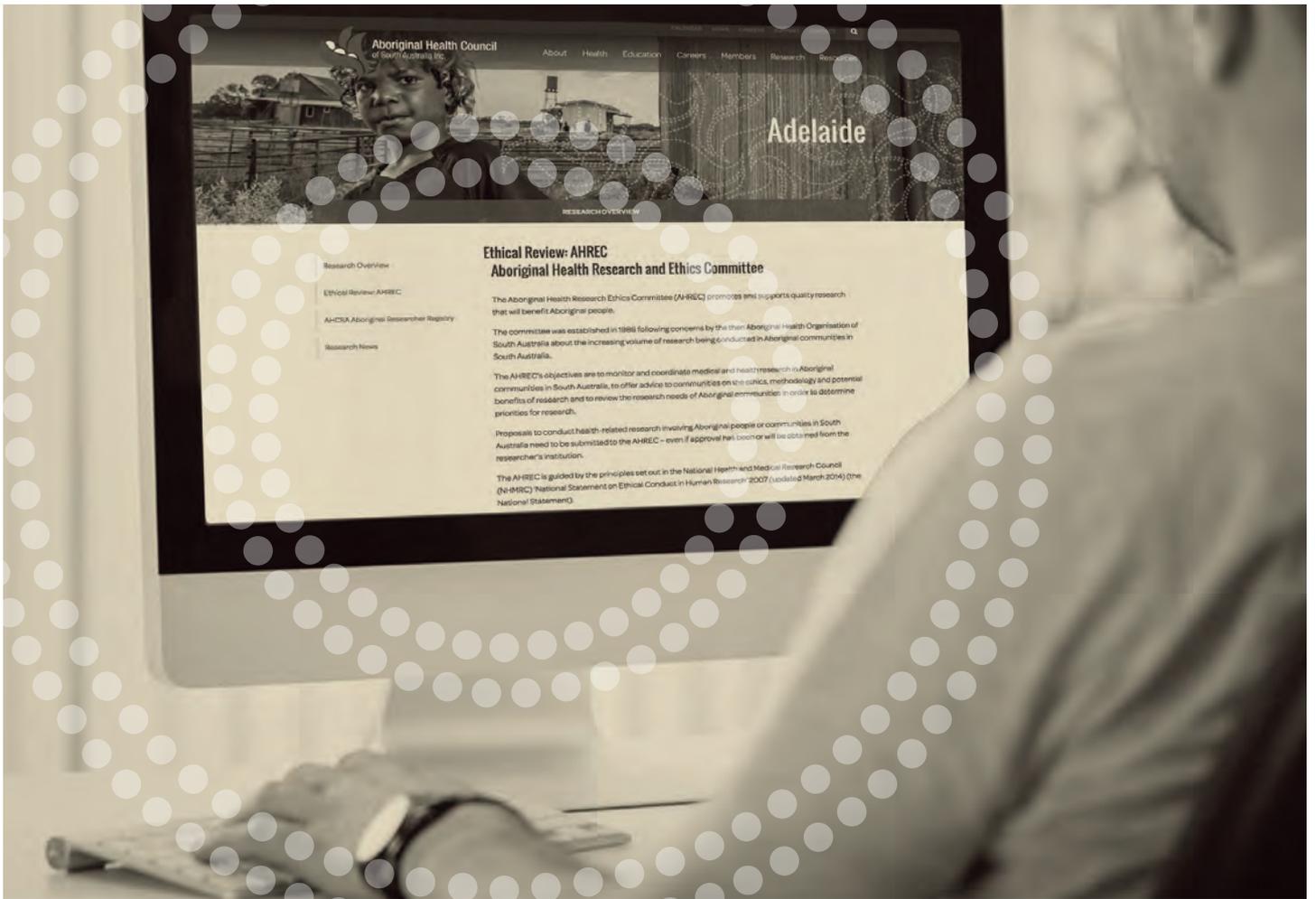
THE RISING SPIRITS COMMUNITY RESILIENCE PROJECT

The study was led by AHCSA and interviewed 134 people across South Australia, including the leadership at ACCHOs, Elders, community members and health workers. The findings were corroborated throughout the project, and finally at a statewide forum, knowledge translation activities took place.

The project has exposed a number of gaps which can only be filled if Aboriginal social and emotional wellbeing and mental health programs:

- Are developed according to the guiding principles of the National Strategic Framework for Aboriginal and Torres Strait Islander People's Mental Health and Social and Emotional Wellbeing.
- Employ at least 75% Aboriginal staff, wherever possible.
- Apply the South Australian Health Aboriginal Health Impact Statement Policy for programs within South Australia.
- Support their staff to undertake training in a Social and Emotional Wellbeing (SEWB) course recommended by the state ACCHS peak body.
- Increase the number of skilled male and female Aboriginal workers in counselling and suicide prevention.
- Provide culturally-appropriate information to be adapted for use by Aboriginal communities, services and funeral directors about Aboriginal cultural safety; writing wills and advanced care directives; establishing trust funds; funeral funding, planning and insurance; cultural ways of grieving and bereavement.

For further recommendations and resources developed by the Rising Spirits study, please access <http://aboriginalgriefandloss.ahcsa.org.au/>



- 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 five 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, SA Health, the National Health and Medical Research Council (NHMRC) and other relevant bodies.

Research into Aboriginal health and wellbeing needs to focus on the interconnectedness between cultural, spiritual, social and physical factors

AHREC Members: The Role of Ethics in Closing the Gap

Messages from AHREC Members who have shared their opinions on the role of ethics in closing the gap in Aboriginal health

To ensure research is undertaken with our people in a safe, culturally appropriate and ethical way in order to provide evidence on measures to support the increase of our life expectancy and improve our quality of life.

Ethical research in an Aboriginal context should primarily be for the benefit of those being researched and/or the community, not the researcher. Research that leads to better health outcomes for Aboriginal people should be the principal goal if we are to 'close the gap' in health outcomes.

The role of research ethics is important in closing the gap as it ensures only research of the highest quality is conducted with our communities. Research must be of real benefit. These benefits must be significant enough to justify the time our communities invest in the research.

Ethics have the utmost importance when overseeing any research done on Aboriginal Australians. The legacy of poorly done and inappropriate research on our peoples has made it the highest priority to consider when intending on contemporary research. We have a duty to protect our communities from any further harm and to ensure that the historical frequency of badly done research does not occur again. If the research does not benefit our communities....then it is poor research! We will not continue to be 'objects of study', and Aboriginal people must be the ones to decide what research is appropriate for US. The committee consists of experienced and dedicated people, both Aboriginal and non-Aboriginal that will always ensure cultural sensitivity and ensure all research adheres to the ethical standards required.

Decisions made by the Committee are based on the values and ethics of research as defined by Aboriginal and Torres Strait Islander peoples. By implementing the ethical guidelines we are informing research that is done the right way, as prescribed by Aboriginal and Torres Strait Islander peoples. The processes and outcomes of this research will contribute to closing the gaps in health disparities and life expectancy.

One definition of ethics is 'moral principles that govern a person's behaviour or the conducting of an activity'. Ethical beliefs therefore 'shape the way we live – what we do, what we make and the world we create through our choices' (ethics.org.au). It is immediately obvious then, that ethics is intricately and intimately connected to social justice and closing the gap in inequity and inequality.

Cover Artwork Reference



Cultural Maintenance Illustration by Allan Sumner, 2016 | This artwork is a fusion of symbols that represent the values that form the honourable foundation of the Aboriginal Health Research Ethics Committee and protect Aboriginal families and communities across South Australia. It visually pieces together, in waveform, a representation of AHREC's collective cohesion and connectedness. The artwork also reflects AHREC's commitment to monitor and coordinate medical and health research in Aboriginal communities in South Australia.



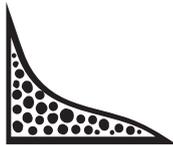
Respect This symbol represents a path leading to the peak of a ridge or hillside. Aboriginal people use these paths as vantage points to view or observe the landscape from a higher point of view, respectfully taking the whole picture into consideration.



Sustainability This symbol represents water and fresh water springs representing the flow of life, renewal and how water sustains life in cycles spanning generations.



Innovation This symbol represents a tree root growing under the ground, and finding its way around obstacles on its journey, creating new paths as it grows bigger and stronger.



Fossils This symbol represents old Aboriginal artefacts that are found buried beneath the surface of our land and sea speak to our ancestral past and influence our present and future.



Culture The centre of Aboriginal being is our culture - it is our home and our comfort - our safe place. This symbol represents that shelter and the cultural collective of Aboriginal community groups across South Australia.



Inclusiveness This symbol represents the coming together of health professionals, providing collaborative opportunities for people to learn about health issues for Aboriginal people.



Accountability Two journey lines that are similar but not the same, represent Aboriginal elders who are responsible for teaching our young ones, and leading them on the right path. Their approach may not be the same, but their message is consistent.



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