



**SAHMRI**  
South Australian Health &  
Medical Research Institute



WARDLIPARINGGA

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*Aboriginal research in Aboriginal hands*

*South Australian Aboriginal Health Research Accord*

*Companion Document*

*2 September 2014*



South Australian Aboriginal Health Research Accord: Companion Document

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## CONTENTS

<b>CONTENTS</b> .....	<b>1</b>
<b>FOREWORD</b> .....	<b>1</b>
<b>INTRODUCTION</b> .....	<b>2</b>
<b>METHOD</b> .....	<b>4</b>
<b>EXISTING NATIONAL AND INTERNATIONAL FRAMEWORKS</b> .....	<b>5</b>
<b>WHAT DO WE MEAN BY COMMUNITY CONSULTATION?</b> .....	<b>7</b>
<b>WHO DOES THE ACCORD APPLY TO?</b> .....	<b>8</b>
<b>KEY PRINCIPLES</b> .....	<b>9</b>
<b>CONCLUSION</b> .....	<b>24</b>
<b>REFERENCES</b> .....	<b>25</b>
<b>CONSULTATION</b> .....	<b>28</b>
<b>SIGNATORIES</b> .....	<b>29</b>



## FOREWORD

It is a privilege to write a few words to introduce this thoughtful document.

The South Australian Aboriginal Health Research Accord had its genesis in two major workshops and a series of consultations with Aboriginal Elders, organisations and community members. Finally, the Accord has been endorsed by the Council of Elders of South Australia, the Aboriginal Health Council of South Australia, the South Australian Health and Medical Research Institute (SAHMRI) and all three South Australian university vice-chancellors to guide Aboriginal research into the future.

Newcomers engaging with Aboriginal communities have repeatedly failed to grasp the depth of relationships, responsibilities and obligations that exist within Aboriginal communities, particularly as it relates to the kinship network. I am aware that there are many who are keen to learn and understand about Aboriginal life. This document will be valuable for anyone who wishes to work differently so they do not make the same mistakes which cause offense or harm. The Accord contains the essence of ideas which, if practised, will lead to successful and mutually productive research partnerships and activities.

Principles are set out to guide researchers through the complexity of working in equivalent inter-cultural partnerships. I was introduced to this way of working 30 years ago by Andrew Spencer Tjapaltjarri, an Elder from the Western Desert, who became my mentor and teacher. Through Andrew's wisdom and generosity of spirit, I received the gift of being able to listen and learn. Moving from that foundation, we were able to work the right way with the community through traditional Aboriginal family values and the kinship structure.

I urge readers to embrace this way of working and congratulate SAHMRI Wardliparingga and their partners on this landmark work.

***Christine Franks***

*Cultural Consultant to Wardliparingga*

*September 2014*

## INTRODUCTION

The South Australian Health and Medical Research Institute (SAHMRI) was incorporated in 2009, as South Australia's first independent health and medical research institute. SAHMRI is unique amongst Australian research institutes in that its founding members are the Government of South Australia and the three major South Australian universities: the University of Adelaide, the University of South Australia and Flinders University. SAHMRI focuses on the major health challenges facing the South Australian population now and for generations to come. SAHMRI's seven research themes reflect these challenges: Cancer; Heart Health; Healthy Mothers, Babies and Children; Infection and Immunity; Mind and Brain; and Nutrition and Metabolism. Aboriginal and Torres Strait Islander health is considered such a central priority, it has been woven across all research themes and activities. The development of SAHMRI allows South Australia (SA) to consolidate and enhance its position in the health and medical research sector, nationally and internationally. SAHMRI will seek to build the capacity of all research activity in SA, with the goal of creating a 'culture of excellence' in health and medical research across the state.

Wardliparingga is SAHMRI's Aboriginal and Torres Strait Islander health research program unit. Wardliparingga has a focus on overcoming the disparities in health status that exist between Aboriginal and non-Aboriginal people, through a focus on better systems of management of chronic disease, psychosocial determinants and consequences of disease, population and social inequity, health system reform, translation of research knowledge into policy and practice, and the capacity strengthening and support of Aboriginal communities, health practitioners and researchers alike. Since its inception, Wardliparingga has been committed to developing and maintaining strong relationships and connection to the Aboriginal community and organisations in South Australia.

The first step in Wardliparingga understanding the landscape of Aboriginal health and health research in SA involved a workshop in February 2013. The workshop was attended by over 80 participants from various backgrounds including full and part time researchers, Aboriginal and non-Aboriginal people and service providers conducting research in their workplace, clinicians, Aboriginal community members, policy and program staff in government, health service planners and decision

makers. The workshop provided an opportunity for participants to reflect on research projects they had either conducted or participated in.

Participants were asked to discuss current issues and experiences in research. This was done in groups that explored barriers to research, existing research strengths, gaps in skills and the types of research conducted, current collaborations and how they worked, and known impacts of research on policy and practice. The workshop also incorporated discussion on future research priorities and the role of Wardliparingga. Several themes emerged including the importance of community control and engagement; the need for research to be done the 'right way'; a focus on the social determinants and cross-sectoral research; building research capacity; knowledge translation; and sustainable funding.

The Accord represents Wardliparingga's response to one of these identified priorities: ensuring that research is done the right way.

## METHOD

In order to construct a guide on doing research the right way, literature was reviewed that focused on best practice in conducting health research with Indigenous populations both internationally and nationally. Importantly, this included reviewing contemporary material, guidelines and existing policies:

- the Aboriginal Health Council of South Australia (AHCSA) (Indigenous Health Research Scoping Study 2005);
- the National Health and Medical Research Council *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*;
- the Australian Institute of Aboriginal and Torres Strait Islander Studies, *Guidelines for Ethical Research in Australian Indigenous Studies*;
- the Canadian Institutes of Health Research, *Ethics of Health Research involving First Nations, Inuit and Métis People*;
- the Canadian Institute for Health Research *Code of Conduct*.

The high level principles that emerged from the literature were then further developed through a series of semi structured discussions with Aboriginal communities, Aboriginal health service providers, key stakeholders, researchers and senior academic staff within South Australia's three major universities.

The practical implementation of the principles was developed by drawing further from the literature to better guide researchers, universities, research institutes, consultants, governments and service providers in the appropriate processes required when developing and conducting health research with Aboriginal people within South Australia.

The South Australian Aboriginal Health Research Accord provides a voice for Aboriginal communities to inform researchers, universities and institutes on how they would like health research to be conducted in their communities.

It is important to note that the Accord does not supersede the principles and objectives of existing national statements or ethics guidelines (such as NHMRC or AIATSIS). Rather, the Accord compliments these and provides an account of the South Australian Aboriginal community's expectations of how research with, for and by Aboriginal people should be developed and conducted.

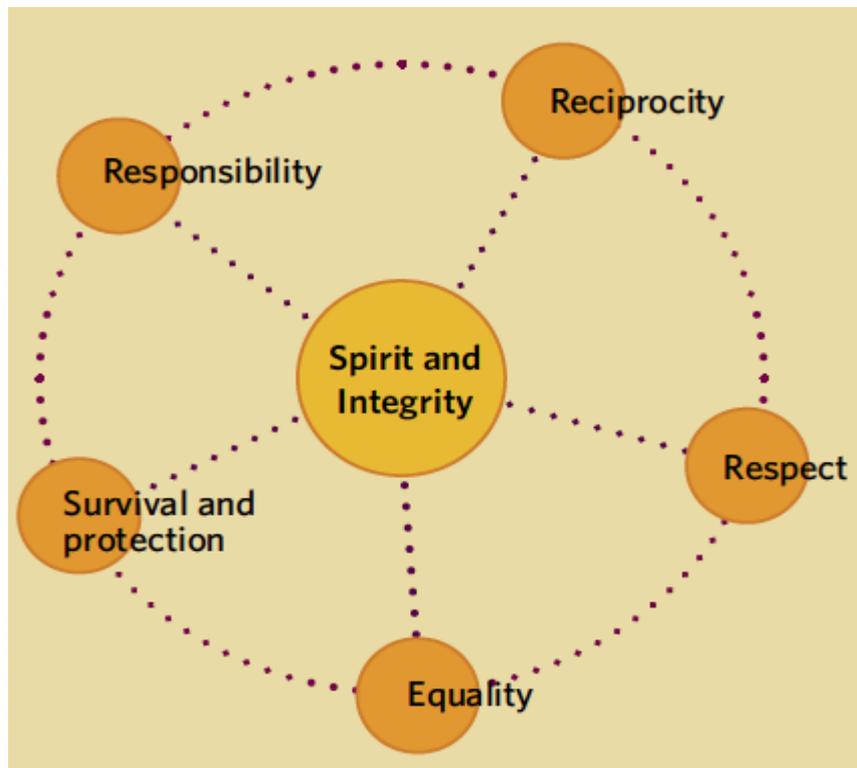
## EXISTING NATIONAL AND INTERNATIONAL FRAMEWORKS

The United Nations Declaration on the Rights of Indigenous peoples<sup>1</sup> provides an important framework for aligning the standards of the Accord. The UN Declaration affirms the principle of Indigenous self-determination, and recognises and respects the contribution of Indigenous knowledge systems, cultures and traditions to contemporary life. Indigenous peoples have the right to practice their cultural traditions, and importantly have a right to maintain and protect the past, present and future of their cultures.<sup>1</sup> The Declaration also supports the rights of Indigenous peoples to exercise their rights within agreements and other arrangements with States.<sup>1</sup>

The Australian Government is a signatory to the United Nations Declaration on the Rights of Indigenous Peoples as of April 2009, and it has been cited as an instrument to support working together in trust and good faith for the advancement of human rights and of closing the gap between Indigenous and Non-Indigenous Australians.<sup>2</sup>

Alongside this, authoritative national guidelines exist, such as the National Statement on Ethical Conduct in Research Involving Humans<sup>3</sup> and 'Values and Ethics: *Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*'.<sup>4</sup> Health research involving Aboriginal and Torres Strait Islander peoples must meet the requirements of both the National Statement and the Aboriginal and Torres Strait Islander specific guidelines.<sup>4</sup>

The NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (2003) identify six core values (see Figure 1) of conducting health research with Aboriginal and Torres Strait Islander peoples. These six core values provide a sound platform for health researchers when engaging in Aboriginal health research and if followed are more likely to meet the expectations of Aboriginal organisations, communities and individuals.



*Figure 1. Six core values of Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*

In South Australia, any health related research proposals involving Aboriginal people or communities must be submitted to the Aboriginal Health Research Ethics Committee managed by AHCSA. All ethics applications must include evidence of engagement, advice and an assessment by Aboriginal communities and/or Aboriginal organisations of the research prior to application submission.<sup>6,7,8</sup>

Projects most likely to ensure successful outcomes for both the researcher and the Aboriginal community incorporate a comprehensive engagement process that engages Aboriginal leadership, has a participatory process and considers resources, governance and strengthening capacity. The Accord aims to provide guidance to these elements through its principles.<sup>9</sup>

## WHAT DO WE MEAN BY COMMUNITY CONSULTATION?

Aboriginal people and communities are diverse across South Australia. Therefore, it is critical for researchers to conduct broad consultation with Aboriginal community organisations and community groups prior to the establishment of research proposals. This should include conversations with Aboriginal Community Controlled Health Services and other social service organisations, women, men and elders groups. It is reasonable to expect that there is potential for numerous perspectives and possible competing interests, which can impact on research. It is recommended that researchers engage with local expert assistance at the commencement, to ensure appropriate engagement and consultation occur with host communities.<sup>10</sup>

## WHO DOES THE ACCORD APPLY TO?

We feel that the Accord can and should apply to all health or medical research that directly involves Aboriginal and Torres Strait Islander peoples. These principles must be considered for any research project that includes Aboriginal participation. Importantly, in following the principles of the Accord, it is also likely that the researcher is also fulfilling their ethical obligations as outlined in the NHMRC Guidelines for Ethical conduct in Aboriginal and Torres Strait Islander Health Research.<sup>4</sup>

The Accord's principles were derived from the literature and the 2013 Wardliparingga Aboriginal health workshop through thematic analysis. Consultation on the potential principles has occurred with Aboriginal peak bodies within South Australia, community elders, CAESA, AHCSA and the university sector.

## KEY PRINCIPLES

The following descriptions provide an explanation for each of the nine identified principles of the Accord. References are provided for further information on best practice and guidelines identified in the literature along with other recommended readings.

**PRIORITIES:** Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability.

**INVOLVEMENT:** The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research.

**PARTNERSHIP:** Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures.

**RESPECT:** Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge.

**COMMUNICATION:** Communication must be culturally and community relevant and involve a willingness to listen and learn.

**RECIPROCITY:** Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.

**OWNERSHIP:** Researchers should acknowledge, respect, and protect Aboriginal intellectual property rights and transparent negotiation of intellectual property use and benefit sharing should be ensured.

**CONTROL:** Researchers must ensure the respectful and culturally appropriate management of all biological and non-biological research materials.

**KNOWLEDGE TRANSLATION:** Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice.

## **Principle 1. PRIORITIES:**

*Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability.*

Formal engagement with both communities and Aboriginal service providers must happen at the development phase of any research. Aboriginal communities and organisations should be involved in prioritising, designing, implementing and evaluating research.<sup>11</sup>

It may be necessary to redesign methodologies to make them more focused on establishing and building relationships. Moreover, timeframes often underestimate what is required for thorough engagement and consideration by communities.<sup>9,12</sup>

### Recommended reading:

Hunt J. Engagement with Indigenous communities in key sectors. Resource sheet no. 23. Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies [internet]. 2013 [cited 2014 Aug 13]. Available from: <http://www.aihw.gov.au/uploadedFiles/ClosingTheGap/Content/Publications/2013/ctgc-rs23.pdf>

Hunt J 2013. Engaging with Indigenous Australia—exploring the conditions for effective relationships with Aboriginal and Torres Strait Islander communities. Issues paper no. 5. Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies [internet]. 2013 [cited 2014 Aug 13]. Available from: <http://www.aihw.gov.au/uploadedFiles/ClosingTheGap/Content/Publications/2013/ctgc-ip5.pdf>

## **Principle 2. INVOLVEMENT:**

*The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research.*

Formal research agreements need to be developed based on the achievement of equivalent intercultural partnerships.<sup>7,13 7,14,15</sup> Consultation with authoritative local community members and organisations (eg: Elders, Aboriginal Community Controlled Health Services and Community Councils) are critical to the engagement process.<sup>11</sup>

Significant diversity exists within and across Aboriginal communities and generalisations should be avoided. Prospective researchers have a responsibility to be informed of, and adhere to, local Aboriginal cultural protocols.

Before commencement of any research, an Aboriginal reference group should be established to address community priorities and provide guidance through each stage of the research process to completion. The reference group should be comprised of individuals with the authority and capacity to consider issues such as community demographics, cultural protocols and gender balance.<sup>11</sup>

Aboriginal communities and services can suspend or withdraw from any research if there is a breach of agreement or dissatisfaction with the implementation and conduct of the project.<sup>5</sup>

### Recommended reading:

Australian Institute of Aboriginal and Torres Strait Islander Studies. Guidelines for Ethical Research in Australian Indigenous Studies [internet]. 2011 [cited 2014 Aug 13]; Available from: <http://www.aiatsis.gov.au/files/research/ethics.pdf>

Laycock A, Walker D, Harrison N, Brands J. Researching Indigenous health: a practical guide for researchers. Melbourne: The Lowitja Institute; 2011.

### **Principle 3. PARTNERSHIP:**

*Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures.*

Aboriginal people must play an integral part in research on issues that affect their lives and communities.<sup>16</sup> The skills, knowledge, wisdom and capacity within Aboriginal communities are important resources that can be used to develop, implement and learn from research. In addition, many organisations exist, both Aboriginal and non-Aboriginal, that can support the development and translation of research. In order to achieve these aims, existing skills and capabilities should be acknowledged, respected and shared by developing partnerships with individuals and local communities.<sup>10,11,19,17</sup> A key focus of any research should involve discussion and development of such partnerships. The balance of power in decision-making should reside with Aboriginal people, for whom the research is proposed to be of benefit.

Researchers should consider formally employing Aboriginal community members for the project, and factor that cost into research budgets.<sup>14,18,19</sup> Working in intercultural partnerships will increase the ability of any non-Aboriginal researcher to understand and learn from Aboriginal knowledge systems. Partnerships can be formed with cultural mentors and / or Aboriginal researchers.<sup>11</sup>

All individual and community contributions to the processes that guide and ensure the delivery of the research must be acknowledged and recognised in publications.<sup>7, 11,14,20</sup> Where Aboriginal community members contribute to the research (not as employees), a fee should be considered and negotiated between the parties.<sup>12</sup>

*Recommended reading:*

National Health and Medical Research Council. The NHMRC Road Map II: A strategic framework for improving the health of Aboriginal and Torres Strait Islander people through research [internet]. 2010 [cited 2014 Aug 14]. Available from:

[https://www.nhmrc.gov.au/files\\_nhmrc/publications/attachments/r47.pdf](https://www.nhmrc.gov.au/files_nhmrc/publications/attachments/r47.pdf)

Australian Institute of Aboriginal and Torres Strait Islander Studies. Guidelines for Ethical Research in Australian Indigenous Studies [internet]. 2012 [cited 2014 Aug 13]; Available from:

<http://www.aiatsis.gov.au/files/research/ethics/GERAIS.pdf>

Franks C, Curr B. Keeping Company an inter-cultural conversation. 2nd ed. (Foster J editor) South Australia: Spencer Gulf Rural Health School, Whyalla, University of South Australia and University of Adelaide; 2007.

#### **Principle 4. RESPECT:**

*Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge.*

Aboriginal people have maintained and protected their cultural knowledge, systems and practices for many thousands of years. In the past, researchers have failed to honour and respect Aboriginal knowledge, cultural expressions and community systems.<sup>7,14</sup> Aboriginal people have authority over Indigenous knowledge, and communities will always seek to protect private cultural knowledge and practices.<sup>7,16</sup> Researchers will need to demonstrate how they have respectfully included Aboriginal knowledge and how that knowledge is recognised and protected. Communities are diverse and therefore protocols may vary and each should be respected as such.

It is always desirable that methodologies be investigated anew so they can be adapted to represent Aboriginal worldviews of research, through working in equivalent intercultural partnerships with communities.<sup>6,20,21</sup>

#### Recommended reading:

Rigney L-I. *Internationalisation of an Indigenous Anticolonial Cultural Critique of Research Methodologies: A Guide to Indigenist Research Methodology and Its Principles*. Emergent Ideas in Native American Studies [internet]. 1999 Autumn [cited 2014 Aug 14]; 14(2):109-121. Available from:

<http://www.jstor.org.ezlibproxy.unisa.edu.au/stable/1409555>

Henry J, Dunbar T, Arnott A, Scrimgeour M, Matthews S, Murakami-Gold L, Chamberlain A. (2002) *Indigenous Research Reform Agenda: Rethinking Research Methodologies*, Links monograph series, v. 2, Melbourne: Cooperative Research Centre for Aboriginal & Tropical Health.

Franks C, Curr B. Keeping Company an inter-cultural conversation. 2nd ed. (Foster J editor) South Australia: Spencer Gulf Rural Health School, Whyalla, University of South Australia and University of Adelaide; 2007.

## **Principle 5. COMMUNICATION:**

*Communication must be culturally and community relevant and involve a willingness to listen and learn.*

Respecting Aboriginal time and space is a critical element for any research to ensure its success.<sup>7,22,20</sup> Individuals and communities may require additional time to consider aspects of research, to ensure protocols are not breached before agreement is reached.<sup>7</sup> It is essential to understand that Aboriginal communication styles differ significantly from non-Aboriginal communication styles. Therefore, time will need to be allocated within project timelines to cater for Aboriginal decision making processes.<sup>23</sup> Communicating any proposed research should consider the audience to be engaged, and ensure that the communication is presented to communities using appropriate language - not in research or corporate jargon.<sup>23</sup>

It is important to explain and document all aspects of the research including the use of equipment and tools.<sup>11</sup>

For many Aboriginal communities, English is not their first or second language. Researchers may therefore need to employ Aboriginal interpreters.<sup>23</sup>

Aboriginal community priorities may differ significantly from that of the researcher for cultural and community reasons. These may include sorry business or cultural obligations and events. These factors need to be incorporated into project timelines, and be respected by the researcher.<sup>7</sup>

Recommended reading:

National Health and Medical Research Council. The NHMRC Road Map II: A strategic framework for improving the health of Aboriginal and Torres Strait Islander people through research [internet]. 2010 [cited 2014 Aug 14]. Available from:

[https://www.nhmrc.gov.au/files\\_nhmrc/publications/attachments/r47.pdf](https://www.nhmrc.gov.au/files_nhmrc/publications/attachments/r47.pdf)

Department for Health and Ageing. SA Health guide for engaging with Aboriginal people [internet]. 2013 [cited 2014 Aug 08]. Available from:

<http://www.sahealth.sa.gov.au/wps/wcm/connect/b9a2f58042371fd89d6ffdef0dac2aff/SA+Health+Guide+to+Engaging+with+Aboriginal+People.pdf?MOD=AJPERES&CACHEID=b9a2f58042371fd89d6ffdef0dac2aff>

Franks C, Curr B. Keeping Company an inter-cultural conversation. 2nd ed. (Foster J editor) South Australia: Spencer Gulf Rural Health School, Whyalla, University of South Australia and University of Adelaide; 2007.

## **Principle 6. RECIPROCITY:**

*Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.*

Aboriginal communities and health services are frequently under-resourced and overburdened.<sup>10</sup> Community members and leaders often carry large responsibilities to maintain services, community governance systems, and provide constant support in relation to cultural matters, family responsibilities and community obligations. In many instances, most of this work is voluntary or expected, and frequently, the same individuals or organisations within communities are approached to support research and other community-based projects from many differing groups. In this context, it is entirely reasonable for Aboriginal communities or Community Controlled Services to expect something back for their involvement in research.<sup>4,19</sup>

Research benefits universities, institutions and individual researchers in many ways (e.g. ownership of knowledge, patents, journal articles and books). Potential benefits should be identified and ways found to share them with local communities.<sup>12,15</sup> Research should not further deplete resources in communities, and the likely human, time and financial costs of engagement should be clearly and honestly discussed and the appropriate support negotiated.

Prior to consulting with community, researchers should think about the allocation of finances and resources to compensate the community's contribution to the research.<sup>19</sup>

The following points are strongly suggested to guide researchers with:

- Employment of Aboriginal researchers
  - Communities and health centres have within them many members who have undertaken Cert IV Indigenous Research Capacity training or have other research experience;
- Training opportunities for local community members;
- Flexible reimbursement options for community members for their contribution to the research;
- Recognition of cultural knowledge and practices;
- Reimbursement of community and health services for workforce contributions to the research.<sup>11</sup>

The Aboriginal community should be able to decide that their participation in the research process does not disadvantage them<sup>4</sup>. Benefits from the research

should be discussed with communities once they have had a suitable time to consider the proposal.<sup>7,14,24</sup> Researchers must be committed that their research aims to provide some benefit for Aboriginal communities from the outset. Researchers have an obligation to ensure their research has the ability to improve health and social change.<sup>12,25</sup>

*Recommended reading:*

Australian Institute of Aboriginal and Torres Strait Islander Studies. Guidelines for Ethical Research in Australian Indigenous Studies [internet]. 2012 [cited 2014 Aug 13]; Available from:

<http://www.aiatsis.gov.au/files/research/ethics/GERAIS.pdf>

Jamieson LM, Paradies YC, Eades S, Chong A, Maple-Brown L, Morris P, Ballie R, Cass A, Roberts-Thomson K, Brown A. Ten principles relevant to health research among Indigenous Australian populations." Med J Aust. 2012;197(1):16-17.

Laycock A, Walker, D, Harrison, N, Brands, J. Researching Indigenous health: a practical guide for researchers. Melbourne: The Lowitja Institute; 2011.

Wand A, Eades S. Navigating the process of developing a research project in Aboriginal health. Med J Aust. 2008;188(10):584-587.

Dudgeon P, Kelly K, Walker, R. Closing the gaps in and through Indigenous health research: guidelines, processes and practices. Australian Aboriginal Studies 2010;2:81-91.

National Health and Medical Research Council. The NHMRC Road Map II: A strategic framework for improving the health of Aboriginal and Torres Strait Islander people through research [internet]. 2010 [cited 2014 Aug 14]. Available from:

<https://www.nhmrc.gov.au/files/nhmrc/publications/attachments/r47.pdf>

## **Principle 7. OWNERSHIP:**

*Researchers should acknowledge, respect, and protect Aboriginal intellectual property rights and ensure transparent negotiation of intellectual property use and benefit sharing.*

Means of respecting and protecting Aboriginal intellectual property should be negotiated at the commencement of the research<sup>7,13,17</sup> and include established mechanisms for reporting on ethical aspects of the project, compliance with NHMRC Values and Ethics Guidelines<sup>4</sup> and the use and benefits of any materials or knowledge used or created during the conduct, or as a consequence of the work. In addition, researchers must be aware that there may exist information that is shared with them that should not be made public to preserve cultural integrity or important cultural protocols. These matters should be negotiated and agreed on prior to the commencement of research.

The following steps are recommended to support the protection of Aboriginal intellectual property and the development and completion of successful research:

- Use clear documentation demonstrating the understanding of the levels of community ownership over any data developed;<sup>7</sup>
- Establish communication processes about all aspects of data collected;<sup>12</sup>
- Describe how individual confidentiality and community anonymity is maintained;<sup>14</sup>
- Plan for ongoing discussion via community reference groups, to ensure cultural protocols are not unintentionally breached;<sup>12</sup>
- Determine how the research findings and any materials developed will be managed, including all dissemination;<sup>11</sup>
- Guidance from community members on if, and how, any cultural knowledge will be used within the research;<sup>7,14</sup>
- Host communities can restrict or refuse use of sacred or traditional cultural knowledge if determined by community processes;<sup>7</sup>
- Negotiate with the community regarding storage and any agreed limitations and/or restrictions on use of data and samples;<sup>26</sup>
- Negotiate the destruction of data or samples with the host community and/or organisation;<sup>11</sup>
- Communicate transparently regarding any commercial application or benefit to the researcher or institution;<sup>14</sup>
- Consent for use of data must be for defined periods of time;
- It is unreasonable to ask for consent to the use of data without an end date or renew period;

- The secondary use of data generated from research for purposes other than its original intent must be negotiated separately with local communities and Aboriginal ethics committees;
- All research results should be presented back and formally signed off at the community level prior to any public discussion, presentations or publication of the findings.<sup>7</sup>

*Recommended reading:*

National Health and Medical Research Council. Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research [internet]. 2003 [cited 2014 Aug 14]. Available from: <http://www.nhmrc.gov.au/guidelines/publications/e52>

Australian Institute of Aboriginal and Torres Strait Islander Studies. Guidelines for Ethical Research in Australian Indigenous Studies [internet]. 2012 [cited 2014 Aug 13]; Available from: <http://www.aiatsis.gov.au/files/research/ethics/GERAIS.pdf>

Jamieson LM, Paradies YC, Eades S, Chong A, Maple-Brown L, Morris P, Ballie R, Cass A, Roberts-Thomson K, Brown A. Ten principles relevant to health research among Indigenous Australian populations. *Med J Aust.* 2012;197(1):16-17.

## **Principle 8. CONTROL:**

*Researchers must ensure the respectful and culturally appropriate management of all biological and non-biological research materials.*

Although biological research can contribute significantly to health improvements for Aboriginal communities, it is a sensitive issue for many individuals and organisations.<sup>27,28</sup> The collection, handling, storage, use, destruction or repatriation of any samples taken during the course of research should form a critical part of the informed consent process, and negotiations with communities and their representative services/governance committees.<sup>29,30</sup>

It is only through transparent negotiations that clarity in appropriate handling requirements, and necessary governance, that arrangements can be established. Suggested discussion items and processes with community members may include:

- Identifying the right people within the kinship network to enable culturally sensitive communication;<sup>31</sup>
- Be transparent and open in communication:
  - a series of conversations with community members may be necessary;
  - establish equivalent partnerships with community members;
  - determine a shared understanding of the proposed research;
  - identify any specific or sensitive cultural matters that may influence the way in which samples should be best managed.
- Establish formal community endorsement for the project to proceed;
- Ensure informed family or individual consent which adheres to local Aboriginal cultural protocols;<sup>7</sup>
- Identify any potential risks or harm to communities and individuals;<sup>4</sup>
- Adhere to all ethical requirements when dealing with biological material;<sup>31</sup>
- Produce protocols relating to the use and storage of biological materials that are agreed to, with clear provisions for withdrawal of samples;<sup>31</sup>
- Any use of samples for secondary purposes will require community consent and approval, without exception;<sup>11</sup>
- Researchers must be prepared for community refusal of research and this must be accepted and respected, irrespective of the stage of the research, even if this involves the destruction of biological material.

Recommended reading:

Tualii M, Davis EL, Braun KL, Tsark JU, Brown N, Hudson M, Burke W. Guidelines for successful engagement to discuss biobanking among Native Hawaiians. *Journal of Cancer Education*. Forthcoming.

Hudson M, Ahuriri-Driscoll A, Lea M, Lea R. Whakapapa: a foundation for genetic research. *Journal of Bioethical Inquiry*. 2007;4:43-9.

Hudson M, Milne M, Reynolds P, Russell K, Smith B. (2010). Te Ara Tika Guidelines for Maori Research Ethics: A framework for researchers and ethics committee members. Health Research Council of New Zealand [internet]. 2010 [cited 2014 Aug 14]. Available from: <http://www.hrc.govt.nz/sites/default/files/Te%20Ara%20Tika%20Guidelines%20for%20Maori%20Research%20Ethics.pdf>

## **Principle 9. KNOWLEDGE TRANSLATION AND EXCHANGE:**

*Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice.*

The need to get research findings into policy and practice is not a new concept.<sup>32</sup> In deed, policy and practice based on the best available evidence is now widely recognised and supported.<sup>33</sup> Knowledge translation is highlighted in the NHMRC principles of reciprocity and benefit to the Aboriginal community.<sup>4,15</sup> Research engaging with communities needs to have concrete ideas of how the findings will see improvements in the health and social and emotional wellbeing of their people.<sup>25</sup>

Therefore, it is important to identify decision makers and leaders who have the interest and ability to implement any such research findings.<sup>34</sup> With this in mind, policy makers, community members and organisations should be involved in the entire research cycle.<sup>33</sup>

Identified strategies on the implementation of findings must be communicated back to communities as a vital link in knowledge exchange.

If these standards are followed, communities will be true partners in integrating research findings and knowledge in policy and practice.<sup>19,32</sup>

### Recommended reading:

Australian Institute of Aboriginal and Torres Strait Islander Studies. Guidelines for Ethical Research in Australian Indigenous Studies [internet]. 2012 [cited 2014 Aug 13]; Available from: <http://www.aiatsis.gov.au/files/research/ethics/GERAIS.pdf>

The Lowitja Institute. Indigenous Research Reform Agenda [internet]. 2012 [updated 2012 Jul 26]; cited 2013 March 4]. Available from: <http://www.lowitja.org.au/indigenous-research-reform-agenda>

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## CONCLUSION

We believe that health research will contribute to closing the health disparity gap between Aboriginal and Torres Strait Islander people and non-Aboriginal Australians. We acknowledge that past practices in health research have harmed Aboriginal people or at best provided limited benefit compared to the benefit to non-Aboriginal researchers. Consultation and feedback with Aboriginal peak bodies, elders groups, stakeholders, researchers and institutions have been incorporated into the development of the Accord. The philosophy and principles of the Accord have been strongly supported by the Aboriginal community. The key messages highlighted in the principles have been further supported by the recent 'Next Steps' project conducted by the Aboriginal Health Council of South Australia, in partnership with the Wardliparingga Aboriginal Health Research Unit of SAHMRI. The 'Next Steps' project identified health research priorities for the South Australian Aboriginal community and how research should be conducted into the future with the Aboriginal health sector. Therefore, we believe it is important to move into the future with agreed approaches for conducting high-quality, respectful Aboriginal health research in South Australia.

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## **CONSULTATION**

In preparing the South Australian Aboriginal Health Research Accord consultation was undertaken with Aboriginal community organisations:

**Aboriginal Health Council of South Australia Board**

**Aboriginal Health Research Ethics Committee**

**Council of Aboriginal Elders of South Australia**

**Grannies Group**

**Northern Aboriginal Elders Group**

**Gully Winds Aboriginal Elders Group**

Consultation within each of the Universities was conducted at various levels with leadership from key personnel in each institution:

**The University of Adelaide**

**University of South Australia**

**Flinders University**

## **SIGNATORIES**

The Accord has been signed by two of South Australia's peak Aboriginal organisations representing the community, and the four South Australian research institutions conducting Aboriginal health research:

**Aboriginal Health Council of South Australia**

**Council of Aboriginal Elders of South Australia**

**The University of Adelaide**

**University of South Australia**

**Flinders University**

**South Australian Health and Medical Research Institute**



The adjacent document is a reproduction of the high level Accord which has been signed by two of South Australia's peak Aboriginal organisations representing the community and the four South Australian research institutions conducting Aboriginal health research on 2<sup>nd</sup> September 2014.

# The South Australian Aboriginal Health Research Accord

Overcoming the health disadvantage experienced by Aboriginal and Torres Strait Islander people represents one of Australia's great challenges. Only through a tangible commitment of time, energy, resources, leadership and collaborative partnership can we hope to make a difference. Research can and should have a role in defining a better way forward for all Australians. The Aboriginal and Torres Strait Islander community has called for reform in the way Aboriginal Health Research is conducted.

We, the undersigned, commit on Tuesday, 2 September 2014 to the conduct of Aboriginal health research in South Australia in accord with the following principles:

**PRIORITIES:** Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability.

**INVOLVEMENT:** The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research.

**PARTNERSHIP:** Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures.

**RESPECT:** Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems, and custodianship of that knowledge.

**COMMUNICATION:** Communication must be culturally and community relevant and involve a willingness to listen and learn.

**RECIPROCITY:** Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.

**OWNERSHIP:** Researchers should acknowledge, respect, and protect Aboriginal intellectual property rights and transparent negotiation of intellectual property use and benefit sharing should be ensured.

**CONTROL:** Researchers must ensure the respectful and culturally appropriate management of all biological and non-biological research materials.

**KNOWLEDGE TRANSLATION:** Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice.

Professor Mike Brooks

The University of Adelaide, Deputy Vice-Chancellor, Research



Professor David Day

Flinders University, Deputy Vice-Chancellor, Research



Professor David Lloyd

University of South Australia, Vice-Chancellor and President



Mr Raymond Spencer  
SAHMRI, Chair of the Board



Mrs Janice Rigney

Council of Aboriginal Elders of South Australia, Chair



Mr Shane Mohor

Aboriginal Health Council of South Australia, Acting CEO



