



Cooperative Research Centre for

**Aboriginal Health**

## **Workshop Report: Aboriginal and Torres Strait Islander people involved in Ethics**

***Sanchia Shibasaki and Paul Stewart***

Report of a workshop held at Yunggorendi Mandé,  
First Nations Centre for Higher Education and Research at  
Flinders University, Adelaide, South Australia, on the 29th October 2003.



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# Table of Contents

<b>Acknowledgments .....</b>	<b>v</b>
<b>Executive Summary .....</b>	<b>v</b>
<b>Introduction .....</b>	<b>1</b>
<b>Workshop Sessions.....</b>	<b>2</b>
<b>Workshop Outcomes .....</b>	<b>3</b>
What is ethics? .....	3
What are your experiences (good and bad) of being involved in assessing the ethics of research projects?.....	3
Good experiences .....	3
Bad experiences .....	4
What are the barriers and facilitators to involving Aboriginal and Torres Strait Islander people in the ethics process? .....	5
Institutional Barriers .....	5
Community Issues.....	5
Facilitators .....	6
What is needed in order for Aboriginal and Torres Strait Islander people and organisations to take control of the research ethics process .....	6
What strategies are needed at the local/state/national level? .....	6
What resources and supports are needed? (eg training, models of consent) .....	7
How do we develop a network? .....	8
<b>Workshop Closing and Summary .....</b>	<b>11</b>



<b>APPENDIX 1</b> .....	<b>13</b>
Workshop Agenda	
<b>APPENDIX 2</b> .....	<b>14</b>
List of Workshop Participants	
<b>APPENDIX 3</b> .....	<b>15</b>
Presentation by Associate Professor Ian Anderson Building copacity in Aboriginal and Torres Strait Islander Research Ethics	
<b>APPENDIX 4</b> .....	<b>19</b>
Presentation on Australian Human Research Ethics Committees by Paul Stewart and Sanchia Shibasaki	
<b>APPENDIX 5</b> .....	<b>29</b>
Workshop Evaluation	
<b>Appendix 6</b> .....	<b>31</b>
Acronyms used in this Report	

# Acknowledgments

The Cooperative Research Centre for Aboriginal Health (CRAH) “Promoting ethical research with Aboriginal and Torres Strait Islander communities” project team would like to acknowledge the Kurna people in welcoming the workshop delegates to country.

The project team also acknowledges the staff at Yunggoendi First Nations Centre for Higher Education and Research, the Facilitator Ted Wilkes, and the delegates who attended the workshop, for all their contributions.

This report was prepared by Sanchia Shibasaki and Paul Stewart, who also co-ordinated the workshop. The authors would like to thank other members of the project team who contributed to the report: Ian Anderson, Terry Dunbar, Angela Clarke and Priscilla Pyett.

# Executive Summary

The workshop provided a forum for Aboriginal and Torres Strait Islander people to describe their experiences and to share and discuss issues regarding ethics and Human Research Ethics Committees (HRECs) relevant to Aboriginal and Torres Strait Islander research.

The workshop identified the importance of developing an Aboriginal and Torres Strait Islander ethics network to:

- engage Aboriginal and Torres Strait Islander people;
- enhance current ethical research processes; and
- influence the Indigenous health research agenda.

The network was also seen as a vehicle for building the capacity of Aboriginal and Torres Strait Islander people involved in human research ethics and to assist and encourage HRECs in Australia to develop formal protocols in assessing ethics applications for research about Aboriginal and Torres Strait Islander people.

To ensure the outcomes of research are beneficial to Aboriginal and Torres Strait Islander communities the network must be a sustainable dynamic tool that will promote knowledge translation about Indigenous health research and ethics.



# Introduction

The workshop for Aboriginal and Torres Strait Islander people involved in Ethics is an outcome of a project developed by the Cooperative Research Centre for Aboriginal and Tropical Health, 'Promoting ethical research with Indigenous communities'.

The purpose of the workshop was to enable Aboriginal and Torres Strait Islander people involved in Human Research Ethics Committees (HRECs) to:

- discuss common issues for Aboriginal and Torres Strait Islander people involved in ethics;
- identify resource and support needs specific to Aboriginal and Torres Strait Islander people involved in the process of ethics assessments; and
- provide a forum in which people can discuss other issues relevant to the ethics of Aboriginal and Torres Strait Islander research.

The workshop was held at Yunggorendi Mande, First Nations Centre for Higher Education and Research at Flinders University, Adelaide, South Australia on the 29<sup>th</sup> October 2003. (See Appendix 1 – Agenda)

Invitations were extended to Aboriginal and Torres Strait Islander people involved in HRECs in the following capacities:

- As members
- As members of Indigenous ethics sub-committees to HRECs, or
- As participants who were asked to advise HRECs on Indigenous projects (See Appendix 2 – List of Participants)

Participants were identified through a survey of Australian HRECs undertaken in 2002 (see Appendix 4 – Ethics Survey Presentation), and through existing contacts with Aboriginal and Torres Strait Islander people known to be involved in ethics.

## Workshop Sessions

The first presentation was from Associate Professor Ian Anderson: Building capacity in Aboriginal and Torres Strait Islander Research Ethics (see Appendix 3). Paul Stewart and Sanchia Shibasaki then presented results from the survey of HRECs in Australia. The survey had aimed to identify all Aboriginal and Torres Strait Islander ethics committees that were registered with the National Health and Medical Research Council of Australia (NHMRC), and to identify processes currently used by HRECs in Australia to make decisions around the ethics of Aboriginal and Torres Strait Islander health research proposals (see Appendix 4).

Participants were then split into three groups and each group was asked to discuss the following topics:

- What is ethics?
- What are your experiences (good and bad) of being involved in assessing the ethics of research projects?
- What are the barriers and facilitators to involving Aboriginal and Torres Strait Islander people in the ethics process?
- In order for Aboriginal and Torres Strait Islander people and organisations to take control of the research ethics process:
  - What strategies (local/state/national) are needed?
  - What resources/supports are needed? (eg training, models of consent)
  - How do we develop a network?

These discussions were fed back to the whole workshop and the outcomes are reported in the next section of this report.

# Workshop Outcomes

## What is ethics?

Participants described ethics as a set of principles that includes the morals of the wider community. These principles should guide good, high quality practice. Participants recognised that ethical principles change over time with changes in society. Ethics involves a values-based framework that establishes standards that guide personal and collective behaviour within society. These values should be consistent with (or determined within) culturally acceptable parameters.

Mainstream ethics includes social justice, empowerment, fairness, the obligation to do no harm, but for Aboriginal and Torres Strait Islander peoples ethics requires that protocols should be set by the Aboriginal and Torres Strait Islander community. Ethics involves issues of control and ownership of research, and issues of Indigenous copyright and ownership of intellectual property. Ethical practice requires that Aboriginal and Torres Strait Islander peoples must be participants (as stakeholders, research participants and researchers) in any research that involves them. They should have full knowledge and understanding of what the research is and what will be the benefits from it. Consent forms should be written clearly in culturally appropriate language. Relevant groups or organisations within the community, including Elders, should be consulted and kept informed of the research.

An important aspect of ethics is the protection of the rights of both the researched and the researchers. When these are balanced, both the researcher and the community benefit from the process of research and these benefits may be long-term or short-term. Researchers should consider the sustainability of the benefit to the community. Research with Aboriginal and Torres Strait Islander communities should involve capacity-building and professional development for Indigenous participants.

## What are your experiences (good and bad) of being involved in assessing the ethics of research projects?

### *Good experiences*

Participants reported that being involved in assessing the ethics of research projects was important for building Indigenous capacity. They were able to offer clarification and to ensure recognition of Aboriginal and Torres Strait Islander protocols. It was useful to be involved from the beginning of a project rather than just during and at the end. Being involved in assessing ethics gave people valuable knowledge of research that was being undertaken over time. It was also important to know the history of a research project. This can provide a safeguard against over-research and abuse. Aboriginal and Torres Strait Islander community involvement led to recognition from the community about some benefits of research. People were more prepared to suggest research topics and questions for research.

## *Bad experiences*

Participants had encountered a lack of understanding from researchers and from HRECs about the process of doing Aboriginal and Torres Strait Islander research, especially in relation to consultation processes, and the amount of time needed to consult with and carry out research with Aboriginal and Torres Strait Islander communities. Timelines were often pushed by researchers seeking fast-track measures to obtain ethics approval. Another problem was that researchers had scope to shop around for a different research site and for another HREC that would approve their project.

There was also a lack of understanding about the complexities of Aboriginal and Torres Strait Islander communities. Most research projects involved poor engagement with the community. Researchers and HRECs often assumed a generic identity to Aboriginal and Torres Strait Islander people: 'You're Aboriginal, therefore you make the decision and speak for [the community].'

Aboriginal and Torres Strait Islander communities need more information and resources to enable them to assess the ethics of research proposals and to engage in meaningful research. Not enough Aboriginal and Torres Strait Islander people are involved in the process. There is only token representation of Aboriginal and Torres Strait Islander people on ethics committees. There is little community awareness about research and ethics. Researchers pay little attention to up-skilling of community.

Informed consent issues were problematic and people raised doubts about the validity of informed consent. Research needs to be explained in language meaningful to the relevant community with local interpretation being clarified. There is often a need for a local interpreter who understands the local community and its customs and can explain the research proposal. Researchers also need to engage with Aboriginal and Torres Strait Islander communities to negotiate ownership of data.

Participants noted that some projects are scientifically sound BUT there could be a sense that there would be no benefits to community. People were concerned about how to deal with these issues: there could be a conflict between a research ethics framework versus people's personal moral viewpoints about what's right.

Both Indigenous and non-Indigenous researchers might be engaging in research for self gain only. Too much research is undertaken in the pursuit of knowledge (often for someone to gain a PhD), rather than with a focus on action and outcomes (problem solving). There was often a lack of clarity about the impact of the research and the benefit (if any) for the community. There was seldom enough feedback to the communities involved in the research; and there was a lack of good follow-up by researchers.

## **What are the barriers and facilitators to involving Aboriginal and Torres Strait Islander people in the ethics process?**

Participants recognised that the barriers and facilitators to involving Aboriginal and Torres Strait Islander people in the ethics process are all affected by the politics of research. Some barriers and facilitators were identified within the institutions and processes of research; others were located within the history, politics and culture of Aboriginal and Torres Strait Islander communities.

### *Institutional Barriers*

The way research funds are granted supports chief investigators applying for multiple grants. Very few Aboriginal and Torres Strait Islander people have any kind of track record for research; hence they can't compete against senior researchers. The university system is very much focussed on academic advancement and not community advancement. Throughout Australia, with few exceptions, there is only token Aboriginal and Torres Strait Islander representation on HRECs. It is difficult for Aboriginal and Torres Strait Islander people on HRECs to assess projects from a wide diversity of academic disciplines. Community members cannot be expected to have background knowledge in all disciplines. Aboriginal and Torres Strait Islander communities involved in research projects have no way of knowing whether researchers have really done what was approved by an ethics committee.

### *Community Issues*

For the Aboriginal and Torres Strait Islander community research is not a priority. The history of research, the abuses of trust, and the way research has been used against Aboriginal and Torres Strait Islander peoples have all contributed to an anti-research mentality in the community.

Participants raised the issue of peak Indigenous bodies/organisations endorsing key research organisations to undertake research in Aboriginal and Torres Strait Islander communities.

Aboriginal and Torres Strait Islander ethics committee members who do not understand research issues and processes do not know enough about research to be able to intervene during the ethical assessment process.

## *Facilitators*

Aboriginal and Torres Strait Islander involvement in ethics processes is facilitated by having strong Aboriginal and Torres Strait Islander people as chairs of HRECs. Aboriginal and Torres Strait Islander members need to be valued as full members of HRECs. More Aboriginal and Torres Strait Islander people might become involved in ethical approval processes if there was a prospect of compensation and reimbursement of out of pocket expenses.

There is a need for raising community awareness concerning research. Regional workshops to develop research capacity in the Aboriginal and Torres Strait Islander community should be funded. There is a need to educate Aboriginal and Torres Strait Islander communities to recognise that ethics applies to us mob too. Community members need to develop expertise in matters relating to research ethics. Ethics should be part of the whole system and not a stand-alone process.

Participants also commented on other aspects of the research process, that could be changed to facilitate more involvement of Aboriginal and Torres Strait Islander peoples. People spoke of the importance of informing and involving people in all aspects of the research process, and of acknowledging all participants in the research process. There is a need for due recognition and respect of Aboriginal workers. They should be recognised and seen as valued members of the research team. Research funding from Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) supports Aboriginal involvement in research.

## **What is needed in order for Aboriginal and Torres Strait Islander people and organisations to take control of the research ethics process**

### *What strategies are needed at the local/state/national level?*

Appropriate resources need to be developed to support Aboriginal and Torres Strait Islander involvement in assessing research ethics. Participants called for changes in university policies to better reflect the issues raised in this workshop.

Participants suggested a set of seven related strategies:

- Develop community owned and controlled research programs. Encourage community ownership of research processes.
- Policy development to implement what we know.
- Respond to community concerns and needs. Ensure ongoing community consultation and effective communication between researchers, ethics committees and Aboriginal and Torres Strait Islander communities.

- Empower Aboriginal and Torres Strait Islander people to ask how to move the research agenda. Set a national strategic agenda around Indigenous research.
- Provide education and training and build capacity in Aboriginal and Torres Strait Islander communities to engage in research. Include awareness of funding processes, timeframe etc.
- Find ways of sharing information and experiences around research ethics. Look at possible ways to do it eg website.
- Make research fun. Create an awareness of good research practises, processes and benefits etc.

Participants also suggested the need for a public awareness campaign about research and research ethics in relation to Aboriginal and Torres Strait Islander communities. National guidelines should be developed for local Indigenous ethics committees: ie think nationally and act locally. Strategies are needed for different models of ethics processes that might be better suited to Aboriginal and Torres Strait Islander communities in different parts of the country. All Aboriginal and Torres Strait Islander ethics committees should be registered with the NHMRC. There is also a need to clarify differences between research, evaluation, performance reviews and audits in regard to the need for ethics approval.

### *What resources and supports are needed? (eg training, models of consent)*

There is a need to develop a resource for HRECs to assess Aboriginal and Torres Strait Islander input into research. The resource would include models and case studies, and structural diagrams. It would provide an interpretation of the NHMRC guidelines for research with Aboriginal and Torres Strait Islander populations. It would explain the inclusion of elders, traditional healers, Aboriginal ministers etc. on HRECs. Ethics guidelines must be flexible enough to allow individual communities to determine appropriate representation on HRECs.

Training for Aboriginal and Torres Strait Islander communities was identified as a critical need. Aboriginal and Torres Strait Islander people involved on ethics committees should provide mentoring and training for other Aboriginal and Torres Strait Islander people. A website could be developed to provide information and support for Aboriginal and Torres Strait Islander people and communities involved in research ethics.

Participants expressed concerns regarding verbal consent. A plain language manual should be developed providing information about all aspects of ethics including consent forms. Examples of consent forms should contain essential components of consent forms not just to reflect the format required by institutions. The manual should also include information about HRECs actual funding and monitoring role in research they approve.

Community programs could be established to:

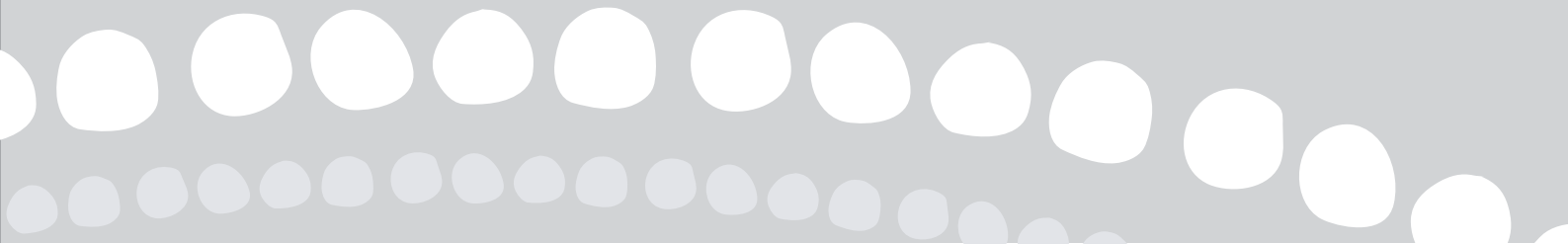
- develop community members' capacity to monitor the research process;
- function as a liaison process between Aboriginal and Torres Strait Islander communities and researchers and HRECs;
- regulate Aboriginal and Torres Strait Islander involvement on national and state bodies;
- obtain and co-ordinate funding for training specifically for ethics issues;
- develop recruitment process to attract participants from communities;
- promote effective research and ethics committee models already available.

Participants suggested the value of identifying local resources and expertise, particularly those people who could provide advice regarding ethics, eg people with experience on land councils. Other resources should be identified at the state or national level could include material, financial, or human resources.

### *How do we develop a network?*

Participants expressed the need for information sharing through a network of Aboriginal and Torres Strait Islander people involved in the ethical approval process. This may involve researchers but most likely non-researchers. Various strategies were suggested, including:

- Email lists
- The Indigenous Researchers Forum
- A national Aboriginal and Torres Strait Islander researchers association
- Using existing bodies already out there – schools, communities, councils
- Consultation with community controlled organisations eg Land councils etc
- Registration of Indigenous Ethics Committees through the NHMRC
- National Ethics Conferences
- List of Aboriginal and Torres Strait Islander representatives on HRECs



Participants stressed the importance of using a suitable format, such as posters, or the web, and using plain English.

Participants recognised the value of trying to identify and assess networks already out there, and to coordinate networks already in existence. However, there would be a need for funding to support a network devoted specifically to Aboriginal and Torres Strait Islander involvement in research ethics. An application to Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) for funding could be developed.



## Workshop Closing and Summary

In the final session of the workshop participants raised a number of additional questions and offered comments from the floor. Some have been included in the previous sections, where relevant. The following issues were also discussed.


How do we get Aboriginal communities to drive the research agenda? Two suggestions were offered in response to this question: through fostering good research processes that are built around effective community involvement; and via strategic avenues that encourage Aboriginal and Torres Strait Islander involvement in research partnerships.

What can be done about the effect of funding deadlines on the involvement of communities in the development of research? The workshop was informed that in 2004 the NHMRC funding rounds would be offering grants to cover the cost of front-end consultation and at the completion of the project for dissemination of information.

Capacity building was again discussed as a critical issue. Participants listed the following key resources needed for building Aboriginal and Torres Strait Islander capacity around research ethics:

- How-to guides
- Examples of best practice
- Case studies
- Links to other networks and resources
- Skills modules
- Short courses
- Examples of consent forms
- Models of HRECs – best practice and examples
- Web-based resources eg e-mail list server
- A network of interested people

Participants felt that capacity around research ethics should be encouraged for Aboriginal and Torres Strait Islander researchers as well as Aboriginal and Torres Strait Islander students, supervisors and examiners.



There were some areas of policy that need to change. The NHMRC's Australian Health Ethics Committee (AHEC) needs to be more flexible with its requirements for ethics assessment. It might be useful if HRECs were assisted and encouraged to develop formal protocols for Aboriginal and Torres Strait Islander health research projects.

At the conclusion of the workshop participants were informed that the project team would produce a Workshop Report that would be sent to participants. The team would also approach the CRCAH to facilitate a network and another meeting to develop resources.

# APPENDIX 1

## Workshop Agenda

**Facilitator: Associate Professor Ted Wilkes**

**Chair – Associate Professor Ian Anderson**

- Welcome – Ted Wilkes
- Kaurua Traditional Welcome – Josie Aguis
- Participant introductions
- Housekeeping
- Presentations –
  - Associate Professor Ian Anderson – Appendix 3
  - Paul Stewart and Sanchia Shibasaki – Appendix 4
- Small Group Work and Feedback
- Workshop Summary – Associate Professor Ian Anderson
- Closing – Associate Professor Ted Wilkes

## APPENDIX 2

### List of Workshop Participants

**Ms Beryl Meiklejohn** (Queensland University of Technology)

**Ms Jill Gallagher** (Vic Aboriginal Community Controlled Health Organisation)

**Ms Denise Groves** (Murdoch University)

**Ms Angela Clarke** (Vic Health Koori Health Research & Community Development Unit)

**Ms Yvonne Cadet James** (James Cook University)

**Ms Lorina Barker** (University of New England)

**Ms Gina Milgate** (University of New England)

**Mr Michael Veasey** (Toowoomba Health Service District)

**Dr Douglas Morgan** (University of South Australia)

**Ms Janice Harris** (University of South Australia)

**Mr Richard McGuinness** (Hunter Area Research Ethics committee)

**Ms Janelle Stirling** (Queensland Institute of Medical Research)

**Ms Audrey Deemal** (Apunipima Cape York Health Council)

**Mr Nigel Bennett** (AIATSIS)

**Mr Shane Houston** (Dept. Health & Community Services NT)

**Dr. Suzi Hutchings** (Aboriginal Health Council Ethics Committee SA)

**Mr Alwin Chong** (Aboriginal Health Council Ethics Committee SA)

**Ms Terry Dunbar** (Cooperative Research Centre for Aboriginal Health NT)

**Associate Professor Isaac Brown** (Northern Territory University)

**Mr Neville Perkins** (University of Southern Queensland)

# APPENDIX 3

## Presentation by Associate Professor Ian Anderson

### *The Context for Developing Indigenous Capacity in Aboriginal and Torres Strait Islander Research Ethics*

In this presentation I want to consider some of the key issues that shape the contemporary context for Aboriginal and Torres Strait Islander health research, and in particular the development of ethical research practice.

#### **The Historical Context to Aboriginal and Torres Strait Islander Research**

- Until the 1960s Aboriginal and Torres Strait Islander people's experience of research was mostly in relation to cultural and physical anthropology
- Biomedical research co-developed with physical anthropology; health research has grown in its own right significantly over last 2-3 decades
- In health research over the last few decades there has been a strong focus on descriptive studies and foundational research, and a correspondingly weak focus on intervention research, evaluative activity and research in urban populations
- There is a strongly developed Indigenous critique of research ethics and practice

#### **Aboriginal and Torres Strait Islander Policy Context**

- |         |   |
|---------|---|
| 1989    | The National Aboriginal Health Strategy (NAHS) was endorsed, signalling a focus on Aboriginal community control, the reform and development of health services, and inter-sectoral strategies through other sectors. Approaches to research were discussed in the Strategy document.  |
| 1991    | The National Health and Medical Research Council (NHMRC) endorsed their interim Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research  |
| 1994-95 | The implementation of the NAHS was evaluated, and the administration of the Commonwealth Aboriginal Health Program was transferred to the Commonwealth Health Portfolio. In this new policy context, priority has been given to the development of strategies to improve Aboriginal health that are evidence-based. Research that addresses the gaps in knowledge critical to the reform of policy and practice has the potential to play a significant role. |

1997 The NHMRC established processes to develop a national strategic (priority-driven) research agenda in Aboriginal health

### **Developing a national strategic (priority-driven) research agenda in Aboriginal and Torres Strait Islander health research**

- In 1997 the NHMRC established the Research Agenda Working Group (RAWG) in Aboriginal Health (a subcommittee of the Strategic Research Development Committee).
- This process was established to focus Aboriginal and Torres Strait Islander health research on strategic research initiatives that address questions critical to the reform of policy and practice, and develop as collaborations between researchers, policymakers, practitioners and Indigenous communities.
- The RAWG in Aboriginal Health has developed process and methods for defining research priorities within particular fields (such as otitis media and diabetes). This has enabled strategic research funding to be provided to nominated priority research projects.
- Assessment criteria for investigator-nominated research proposals were modified to include criteria such as the sustainability of research outcomes, transferability of research findings, and collaboration with Aboriginal and Torres Strait Islander communities.
- In the triennium 2000-2003 the NHMRC undertook (through the Australian Health Ethics Committee) to review the 1991 *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*, and through the RAWG (in Aboriginal Health) to develop a research 'road map' that identified key priorities for Aboriginal and Torres Strait Islander health research.
- In parallel, the Commonwealth Department of Health has commissioned strategic research on priority issues (such as the national expenditure studies) and also commissioned specific research projects to analyse existing evidence in relation to key policy questions (primary health care studies)

### **Changing Context for Research in Aboriginal and Torres Strait Islander Communities**

- Aboriginal and Torres Strait Islander communities have increasing exposure to positive research experiences through research work undertaken in, for example, Aboriginal community-controlled health services and Indigenous-led research programs.

- Growing advocacy within the Aboriginal primary health care services for evidence-based practice (through leadership on the implementation of clinical guidelines)
- Growing advocacy for Indigenous-led research or research that is 'community controlled'
- A debate that has focussed researchers on redefining the terms and process of research practice in Indigenous health contexts.
- Increasing number of Indigenous researchers in health
- Development of Indigenous epistemologies and critiques of 'western knowledge'


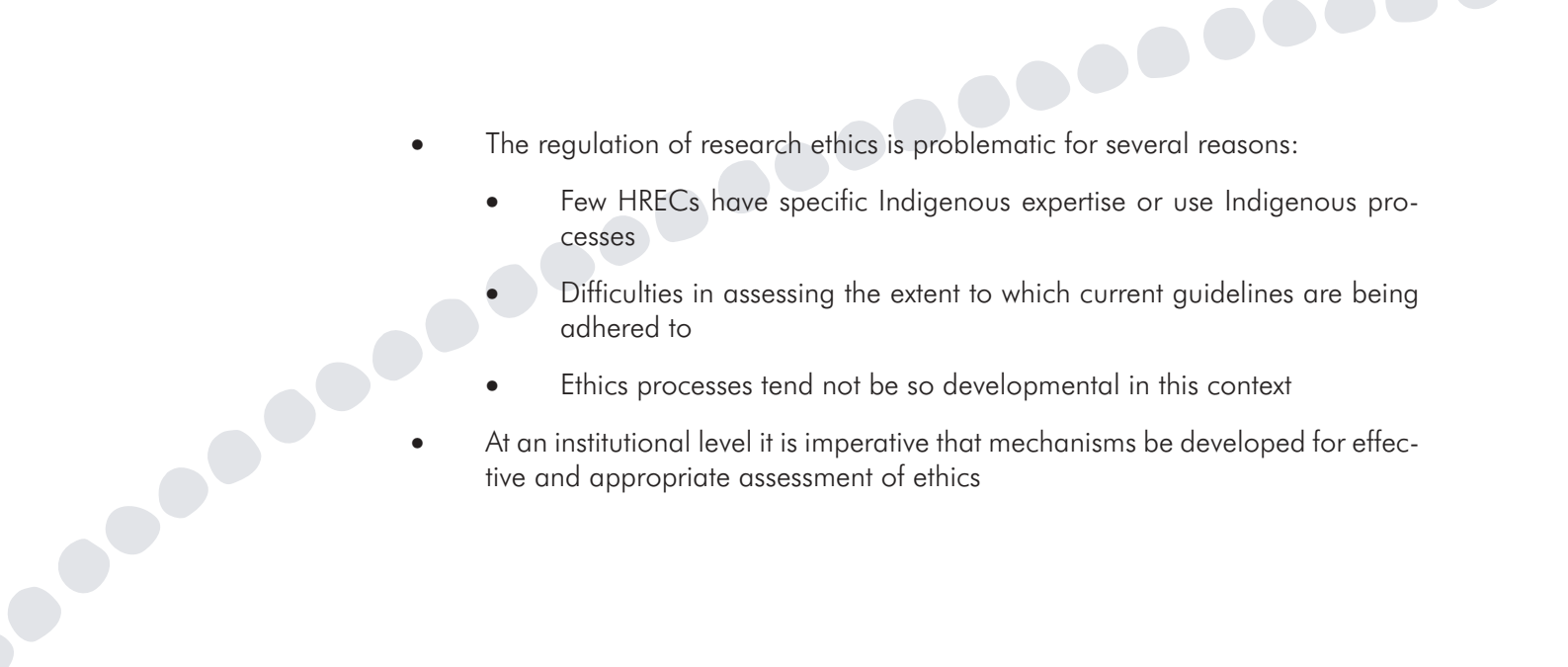
### **Reforming Research Institutions**

Some research institutions and universities have developed initiatives in academic practice that reform the processes of research in order to:

- Address the Indigenous critique of research practice
- Address some of the key reasons for research failure in Aboriginal health, such as:
  - Failure to develop and maintain research collaborations
  - Failure to reach agreement on the ethics of research
  - Failure to develop methods appropriate for the social and cultural context of Aboriginal and Torres Strait Health.

### **Ethics**

- The 1991 NHMRC Guidelines covered issues of community consultation, ownership of data, publication, and community development/benefit to communities
- Newly adopted NHMRC Guidelines have been revised in order to focus on negotiating the ethics of research practice by focussing on understanding the values that Aboriginal and Torres Strait Islander people have with respect to research processes.

- 
- 
- The regulation of research ethics is problematic for several reasons:
    - Few HRECs have specific Indigenous expertise or use Indigenous processes
    - Difficulties in assessing the extent to which current guidelines are being adhered to
    - Ethics processes tend not be so developmental in this context
  - At an institutional level it is imperative that mechanisms be developed for effective and appropriate assessment of ethics

# APPENDIX 4

**Presentation on Australian Human Research Ethics Committees by Paul Stewart and Sanchia Shibasaki**



## Project Team

- Assoc Professor Ian Anderson – Project Leader
- Mr Paul Stewart – Co-Convenor
- Ms Sanchia Shibasaki – Co-Convenor
- Dr Priscilla Pyett
- Ms Angela Clarke
- Ms Terry Dunbar
- Mr Peter Thomsen
- Ms Jeannie Devitt

## Aim

- To establish a database of Australian Human Ethics Committees (AHEC) recognised Ethics Committees
- To identify processes currently used in making decisions around Indigenous research proposals.

Number of AHEC Ethics Committees in Australia by State and Territory, 2002 (n=228)

	QLD	NSW	ACT	VIC	TAS	SA	WA	NT
No. of Committees	42	64	12	64	4	18	21	3

## Process

Date	Contents	Addressed To	Response
23 March 2002	<ul style="list-style-type: none"> <li>•Introductory letter</li> <li>•Information sheet</li> <li>•Survey</li> </ul>	AHEC Committee	70 / 228 (31%) <sup>1</sup>
19 June 2002	<ul style="list-style-type: none"> <li>•Follow up letter</li> <li>•Information sheet</li> <li>•Survey</li> </ul>	Nominated contact person for the committee	37 / 152 (24%) <sup>2</sup>
26 July 2002	<ul style="list-style-type: none"> <li>•Follow up letter</li> <li>•Information sheet</li> <li>•Survey</li> </ul>	Contact person	50 / 114 (44%) <sup>3</sup>



CO-OPERATIVE RESEARCH CENTRE FOR  
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**ETHICS COMMITTEE RESPONSE**

1. Our committee is interested in finding out more about this project: YES  NO

2. The contact person for our committee is:

Position.....

Phone..... Fax: .....

Email.....

3. Other Indigenous ethics committees in our region are: *(details if known)*

.....

.....

4. Our current protocol for processing research involving Indigenous people is:

- (1) our committee is an all-Indigenous member committee
- (2) we refer on to an all-Indigenous Ethics Committee
- (3) we co-opt Indigenous person/s for the particular meeting
- (4) we have permanent Indigenous representation on our committee
- (5) we refer proposal to specified Indigenous person outside the committee process
- (6) other - describe

Thank you for your time

Please Fax response to Jeannie Devitt at Danila Dilba Health Service,  
Darwin 08-8981 3688

Surveys received from AHEC Ethics Committees by  
State and Territory, 2002. (n=228)

	QLD	NSW	ACT	VIC	TAS	SA	WA	NT
<b>No. of Committees</b>	42	64	12	64	4	18	21	3
<b>Surveys received</b>	31	45	7	43	2	15	17	3
<b>Response rate</b>	76%	70%	58%	67%	50%	83%	81%	100%

**Total Response Rate: 163 / 228 (71%)**

**Number of Responses by AHEC Ethics Committees  
to the Survey Questions, 2002  
(n=163)**

	<b>All Indigenous</b>	<b>Refer to all Indigenous Committee</b>	<b>Coopt Indigenous person</b>	<b>Permanent Indigenous representation</b>	<b>Refer to specified Indigenous person outside the committee process</b>
<b>Yes</b>	<b>4</b>	<b>11</b>	<b>30</b>	<b>19</b>	<b>40</b>
No	141	132	113	124	103

Did not answer the question – 20  
No response received ie. Committee did not return the survey - 65

**Responses to Survey Questions**

	<b>QLD</b>	<b>NSW</b>	<b>ACT</b>	<b>VIC</b>	<b>TAS</b>	<b>SA</b>	<b>WA</b>	<b>NT</b>
<b>No. of Committees</b>	<b>42</b>	<b>64</b>	<b>12</b>	<b>64</b>	<b>4</b>	<b>18</b>	<b>21</b>	<b>3</b>
All Indigenous member committee	2	0	0	0	0	0	0	2
Refer to an all Indigenous EC	1	5	0	0	0	5	0	1
Co-opt Indigenous person/s for the particular meeting	9	10	2	5	0	0	4	0
Have permanent Indigenous representation on our committee	6	3	1	2	0	4	2	1
Refer proposals to a specified Indigenous person outside the committee process	8	12	0	12	0	4	4	0

## Other – please describe

Response	No.
No Special Protocols	23
Follow NHMRC Guidelines on Aboriginal and Torres Strait Islanders	7
Have not Received any Indigenous Proposals	22
No Response	7
Unclear Responses	7
Decline to participate	5

## Example of Responses

### **No Special Protocols**

*At the moment we don't have such projects and don't have special protocols set up to deal with them*

### **Follow NHMRC Guidelines on Aboriginal and Torres Strait Islanders**

*Follow NHMRC guidelines re Ethical matters in Aboriginal & Torres Strait Islander health research*

### **Have not received any Indigenous Proposals**

*No research involving Indigenous people has been submitted to our HREC*

## Example of Responses

### No Response

*Thank you for your letter although this is not applicable to my role I would rather not comment. Survey returned blank*

### Unclear Responses

*Hard to imagine how the Sydney IVF Ethics Committee would be able to provide useful input to your project.*

### Decline to participate

*Unfortunately we are unable to participate but we wish you all the best with the project*

## Number of ethics committees interested in finding out more about this project, 2002 (n=163)

	QLD	NSW	ACT	VIC	TAS	SA	WA	NT
<b>No. of Committees</b>	42	64	12	64	4	18	21	3
<b>Yes</b>	<b>23</b>	<b>28</b>	<b>2</b>	<b>23</b>	<b>0</b>	<b>9</b>	<b>12</b>	<b>3</b>

### Aboriginal and Torres Strait Islander ethics committees identified through the project, 2002

QLD	James Cook University
NSW	NSW Aboriginal Health Research Committee Ethics Committee
NT	<ul style="list-style-type: none"><li>▪ Alice Springs Institutional Ethics Committee – sub committee</li><li>▪ Top End Human Research Ethics Committee – sub-committee</li></ul>
SA	Aboriginal Health Council of South Australia
WA	WA Aboriginal Health Information & Ethics Committee

### Outcomes

- Determine current baseline capacity
- Identifying strategies and processes
- Assist in resource development
- Workshop



## Summary

- Very few established formal mechanisms
- Majority of mechanisms are informal




# APPENDIX 5

## Workshop Evaluation

A total of 20 participants attended the workshop not including the Chair, Facilitator and Workshop Planning Group. The total number of evaluation forms received from participants was 15.

The responses received from participants were as follows:

Comment	Response
The workshop was well organised	Strongly Agree 8
	Agree 7
The background information regarding the workshop was relevant and useful	Strongly Agree 8
	Agree 7
The small group work was useful and allowed me to become involved in discussions	Strongly Agree 11
	Agree 4
Information gained from this workshop will enable me to be more effective in my role/ understanding of ethics	Strongly Agree 8
	Agree 5
	Disagree 1
	Blank 1
The venue was appropriate for the workshop	Strongly Agree 8
	Agree 7
Overall the workshop was effective	Strongly Agree 6
	Agree 8
	Blank 1



Participants suggested the following areas of interest they would like included in future workshops:

- Partnerships
- Action-orientated production linking directly to grass roots
- Knowledge of databases available in relation to Aboriginal and Torres Strait Islander health research
- Developing new models for assessing Aboriginal and Torres Strait Islander research proposals
- Power of HRECs
- Implementation processes
- Acknowledging diversity and agreeing on the core common processing principles
- Nature of unethical conduct and processes of dealing with complaints
- Facilitating the move of Aboriginal and Torres Strait Islander research from the university to the community
- Indigenous methodologies

Participants also suggested the value of having a social event such as a dinner to get to know one another, perhaps as a way of establishing a network. The workshop itself was appreciated as a valuable networking opportunity.



## APPENDIX 6

### Acronyms used in this Report

AHEC	Australian Health Ethics Committee
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
CRCAH	Cooperative Research Centre for Aboriginal Health
HREC	Human Research Ethics Committee
NHMRC	National Health and Medical Research Council of Australia





