EVALUATION OF THE NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL DOCUMENTS:

GUIDELINES FOR ETHICAL CONDUCT IN ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH 2004 (*VALUES AND ETHICS*)

AND

KEEPING RESEARCH ON TRACK: A GUIDE FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES ABOUT HEALTH RESEARCH ETHICS 2005 (*KEEPING RESEARCH ON TRACK*)

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1. Executive Summary

This evaluation concerns two documents:

- *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research 2004 (Values and Ethics)*; and
- *Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005 (Keeping Research on Track)*.

The evaluation seeks to provide advice to the National Health and Medical Research Council (NHMRC) on:

- How to improve the effectiveness of the guidelines through interrogating their practical application.
- Training, capacity building, further investigations and/or development of additional appropriate guiding materials.
- Maintaining the contemporary nature of the guidelines through collection of suggested amendments, application and content and coverage issues.

This evaluation used a summative methodology and sought input from a range of stakeholders on how the guidelines were currently being used and processes involved in their application.

In addition, the evaluation team sought advice from stakeholders on what improvements could be made to both documents concerning their content. This report (Sections nine, ten and 11) present the results of the evaluation from the stakeholders' perspective.

Section 12 highlights inconsistencies between Australian ethical guidelines including the *Values and Ethics; Aboriginal Health & Medical Research Council Guidelines for Research in Aboriginal Health – Key Principles*; the *Guidelines for Ethical Research in Australian Indigenous Studies, 2012;* and the *National Statement on Ethical Conduct in Human Research 2007* (updated 2013).

Section 13 includes an examination of the local and international changes in the Aboriginal and Torres Strait Islander health research ethics landscape.

a. Overview of the findings: *Values and Ethics – Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*

Overall there was a mixed response regarding the *Values and Ethics* document. Some people felt it was comprehensive while others suggested that the values could be better explained:

- Many participants felt that the values needed to be supported by the use of examples of good and bad practice as well as key questions or case studies in order to better illustrate their application. People often raised questions such as: What does equality actually mean? How does reciprocity actually work? What does it mean for a project? How can it be enacted?

- It was strongly suggested that the value 'survival and protection' should be framed in more contemporary language. Suggestions to replace this value included 'cultural integrity' or 'resilience'.
- The nature of reciprocity involves negotiation as well as researchers feeding back findings to community. Greater emphasis is needed on translating research back to communities and this could also be articulated under the principle of reciprocity. It should be noted that reciprocity can also be a physical exchange, such as a fridge for the bush clinic or a washing machine that is need by community rather than a cash voucher.
- Additional value – It was suggested that the guidelines need to be more explicit about a principle to formalise relationships to ensure genuine and equal partnership. It was also suggested that 'active listening' be an additional value, although this could be incorporated into the value of partnership.
- A clearer definition of 'health research' is required perhaps in the National Statement, but also in an update of both documents. Incorporating the definition of Aboriginal health and wellbeing into the front end of the document has been suggested.

b. OVERVIEW OF THE FINDINGS: *KEEPING RESEARCH ON TRACK: A GUIDE FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES ABOUT HEALTH RESEARCH ETHICS*

The *Keeping Research on Track* document was particularly well received by Aboriginal and Torres Strait Islander people working in research and non-Indigenous people working in the sector. It was said to be a better format, had a clearer purpose, was easier to follow and was a better document to take to community.

Both community and research participants wanted to see more robust methods for the way research was conducted. Suggestions included the development of templates for research agreements as a suite of template documents.

c. CONTEXT FOR BOTH DOCUMENTS

Many workshop participants felt that more historical context to the ethics documents was needed. Participants felt there will always be new personnel or organisations coming into Aboriginal health research that may or may not have an appreciation of the complexity of Aboriginal health and the associated rationale for ethics guidance. Suggestions for providing deeper background context included:

- Make reference to the International Human Rights documents to ensure that research and research ethics sit within a rights framework;
- Include a well-accepted definition of Aboriginal health;
- Include a section on the history of Aboriginal and Torres Strait Islander people and health;
- Include an outline of Aboriginal and Torres Strait Islander history of health research with a focus on negative experiences in the past;
- Ensure that privilege is given to Indigenous knowledge and cultural practices as part of the ethics and research process.

Inclusion of this context would then provide some explanation and rationale for the need for Aboriginal and Torres Strait Islander health ethics.

d. FORMAT AND PRESENTATION OF REVISED DOCUMENTS

There is an opportunity now to make ethics information more widely available through digital technology to different audiences and using different formats. The NHMRC should consider different formats for wider distribution of ethics information including:

- A central website/clearinghouse site that could include a range of relevant ethics documents, checklists, templates, and information about the ethics process in each jurisdiction as well as international documentation;
- Social media formats such as Facebook or Twitter;
- A logged help site;
- A help hotline;
- The use of 'apps';
- DVDs;
- Training – E.g., conduct local training workshops or use a system similar to the CITI (The Collaborative Institutional Training Initiative) at the University of Miami. CITI is web-based and provides training materials on aspects of ethical research for academic institutions, government agencies, and commercial organizations in the U.S. and around the world (https://www.citiprogram.org/) ;
- Summary documents: all relevant documents should be cross–referenced and contain a glossary of relevant terms;
- Consider documents in language and/or other formats for community; and
- Use Aboriginal iconography to tell the story.

e. TARGETING THE DOCUMENTS TO SPECIFIC AUDIENCES

The lack of awareness of the ethics documents was a consistent theme from the evaluation. As well as reworking ethics documents, efforts should be made to promote and target ethics information to relevant stakeholders by:

- Promoting the ethics information broadly to a wide range of stakeholders (HRECs, researchers, research organisations and community).
- Developing tailored and targeted campaigns to specific stakeholders.

f. INCONSISTENCIES WITH OTHER DOCUMENTS

Comparison of relevant material found that documents such as the AIATSIS Guidelines, and the AH & MRC guidelines are based on different backgrounds and therefore different principles, have a 'bottom up' approach and therefore a more direct focus on the needs of community in the research process. On the other hand, the Values and Ethics document, Keeping Research on Track and the National Statement take a 'top down' , and therefore wider approach, with less detail about specific instruction as to what is needed to support Aboriginal health research.

There is a need also for consistency between the National Statement and the Values and Ethics Document.

g. RECOMMENDATIONS

I. REVISION OF THE DOCUMENTS

With these findings in mind it is recommended that both documents are revised in the following ways:

1. That both documents are developed as companion documents and made available as a set.
2. That both documents are closely cross-referenced to each other and to the *National Statement*.
3. That the *Values and Ethics* document be revised so that the values are more clearly articulated and supported with case studies, good and bad practice examples and key questions.
4. That the value 'Survival and Protection' be renamed in more contemporary language, such as 'Cultural Integrity' and consideration be given to the addition of a further principle around partnership and collaboration.
5. That an additional value about partnership be incorporated.
6. That further work is undertaken to progress community discussion about new technologies such as genetics/genomics, bio-banks, and data-linkage, with a view to development of protocols around these issues.
7. That the historical context of Aboriginal and Torres Strait Islander health is highlighted in the documents including:
    a. A well-accepted definition of Aboriginal health.
    b. Reference to International Human Rights documents to ensure that research and research ethics sit within a rights framework.
    c. A section about the history of Aboriginal and Torres Strait Islander health research with the purpose of providing an understanding of Aboriginal peoples' general mistrust of research. Inclusion of this context would then provide some rational for the need for Aboriginal and Torres Strait Islander health ethics.
8. That the format and presentation of the documents, together with all relevant resources be made widely available within one electronic source such as a central website or other suitable media.   This source could undertake a 'clearinghouse' function and contain all other relevant ethics documents such as checklists, templates and other information about ethics processes in each jurisdiction and the cross-referencing of international documentation.

II. TRAINING AND ORIENTATION FOR STAKEHOLDERS

It has been suggested from this evaluation that the NHMRC develop a strategic approach to promoting awareness, training and competence of the revised Aboriginal and Torres Strait Islander health research ethics documents by including:

1. An engagement program with community stakeholders including meetings, forums, conferences and professional bodies. The engagement process should also seek to increase Aboriginal and Torres Strait Islander understanding of research and its processes and be supported with relevant training materials.
2. A program for all approved ethics committees and members to ensure a high level of confidence and competence in assessing Aboriginal health research proposals.

3. A program for researchers working in the Aboriginal and Torres Strait Islander health research sector. This program should include a particular focus on gaining the understanding of and commitment to the Guidelines by senior leadership in research organisations.

Each program should cover awareness, orientation and training and be tailored accordingly for each stakeholder group.

III. ASSESSMENT AND MONITORING

In relation to the concerns raised through the consultations covering how ethics applications are assessed by committees and monitored, it is recommended that:

1. Human Research Ethics Committees with a specific focus on Aboriginal and Torres Strait Islander health be set up and resourced in those jurisdictions where they do not yet exist, with a national committee or process to consider multi-site, multi-jurisdictional research proposals.
2. HRECs include, as part of the assessment, a monitoring and reporting process on research proposals and verification that communities and/or community organisations will be or have been informed about the Guidelines and supporting documents.
3. A function should be included to monitor continued engagement, involvement and approval for the research project in the HREC annual reports where Aboriginal and Torres Strait Islander health research is being conducted.
4. Evaluations occurring in the Aboriginal health sector are subject to the ethics process.
5. The NHMRC establish a process to identify community based research priorities needs to be established and funded. This might include:
   a. Greater accountability and monitoring in the research proposal development phase
   b. A Community based health Research funding round
   c. As well as training for newcomers, ongoing training resources should also be available.

IV. TARGETING KEY STAKEHOLDERS

In relation to the targeting of key stakeholders it is recommended that:

1. The NHRMC develop and apply an ongoing dissemination strategy to ensure that the Guidelines, supporting documents and resources are contemporary and relevant to all stakeholders. In particular, consider specific communication strategies to ensure relevance of the two documents to the community, such as offering multiple formats including language and media and using Aboriginal iconography to tell the story.

2. INTRODUCTION

a. PURPOSE OF THE EVALUATION

'In our view, there is no point doing research into Aboriginal and Torres Strait Islander health unless it involves Aboriginal and Torres Strait Islander peoples at every step along the way, and that their priorities are the ones that matter most'[1]

In recent decades Aboriginal and Torres Strait Islander peoples, like other Indigenous communities around the world, have led action to change the way research concerning their own lives, is conducted. Many non-Indigenous people have joined in these efforts. Poor research practices have been actively resisted. Ethical processes for research have been strengthened. Research that does not offer benefit has been rejected. There have been calls for more accountability, Indigenous leadership and rights in research.

Ten years ago, the National Health and Medical Research Council (NHMRC) produced two documents relating to Aboriginal and Torres Strait Islander health research ethics:

- *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research 2004 (Values and Ethics).*
- *Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005 (Keeping Research on Track).*

Values and Ethics was developed primarily for researchers and Human Research Ethics Committees (HRECs) to inform them of the complex considerations necessary in designing and conducting appropriate research in Aboriginal and Torres Strait Islander communities.

Keeping Research on Track is the translation of this guideline into concrete expectations, actions and outcomes for all involved in research. *Keeping Research on Track* was designed with attention to increasing accessibility for Aboriginal and Torres Strait Islander communities who may be considering, or are involved in, research.

b. SCOPE OF THE EVALUATION

It is understood that the guidelines are used by, but not limited to:

- Human Research Ethics Committees
- Researchers
- Ethics and Research Office staff
- Aboriginal Health Services and their Boards
- Aboriginal and Torres Strait Islander communities
- Institutions administering federal competitive grant funds such as the NHMRC and Australian Research Council (ARC)

This evaluation sought the engagement of all these stakeholders.

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[1] Foreword – Researching Indigenous health: A practical guide for researchers – the Lowitja Institute 2011

3. METHODOLOGY

The overriding evaluation approach was summative; that is, it attempts to answer the five evaluation questions concerning the effectiveness of reach and implementation of *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research 2004* and *Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005*. Summative evaluations attempt to measure the impact of the program of work (in this case, the implementation of both documents).

4. METHODS

This evaluation used four primary methods to obtain information about the reach and implementation of the guidelines. Each method is described below.

a. NATIONAL CONSULTATIONS

The Evaluation Team conducted workshops in 12 locations around Australia. Each consultation was attended by a project leader from either AIATSIS or the Lowitja Institute and a facilitator. All facilitators are senior, experienced Aboriginal and Torres Strait Islander health researchers well known in the sector. Consultations and were undertaken in every jurisdiction (see Appendix 1, Table 1).

Questions asked at each consultation included:

- Are Aboriginal and Torres Strait Islander communities aware of the documents?
- Have Aboriginal and Torres Strait Islander communities found the guidelines useful and helpful in engaging with ethical research?
- How have Human Research Ethics Committees (HRECs) used the guidelines to undertake ethical review of Aboriginal and Torres Strait Islander health research?
- How have researchers used the guidelines to undertake ethical Aboriginal and Torres Strait Islander health research?
- Is there other documentation, both Australian and international, which could help shape these two documents?
- Given these aforementioned considerations, what improvements to the guidelines could be made?

b. STAKEHOLDER SURVEYS

Eight stakeholder surveys were designed (see Appendix 2) to seek advice on the evaluation questions. The stakeholder surveys were available for:

- Aboriginal and or Torres Strait Islander community members
- Community organisations that conduct research
- HREC administrators
- Researchers
- Ethics committees
- Research institutions/organisations
- Community organisations that participate in research

- Government agencies/departments
- Private organisations and consulting firms

The surveys were hosted on the Lowitja Institute dedicated evaluation webpage at http://www.lowitja.org.au/nhmrc-research-ethics. Over 200 stakeholder surveys were completed throughout the two-month period that the survey was open.

c. WRITTEN SUBMISSIONS

An online submission process where stakeholders could upload their submission was made available via the Lowitja website at http://www.lowitja.org.au/submission-evaluation-research-ethics.

d. LITERATURE REVIEW

A literature review examining changes in the Aboriginal and Torres Strait Islander health research landscape was conducted to inform what changes have occurred in the Aboriginal and Torres Strait Islander Health research since the release of both *Values and Ethics* and *Keeping Research on Track*. A number of other relevant documents relating to health research include:

- *The Declaration of Helsinki* – a set of ethical principles regarding human experimentation developed for the medical community by the World Medical Association (WMA). It is widely regarded as the cornerstone document of human research ethics. It can be viewed online at http://www.wma.net/en/30publications/10policies/b3/17c.pdf;
- The NHMRC *National Statement on Ethical Conduct in Human Research 2007* – which can be viewed online at http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72_national_statement_130624.pdf;
- *Guidelines for Ethical Research in Australian Indigenous Studies* – available online at http://www.aiatsis.gov.au/research/docs/ethics.pdf;
- The Lowitja Institute's *Researching Indigenous health: a practical guide for researchers* – available online at http://www.lowitja.org.au/lowitja-publishing/L009; and
- The Lowitja Institute's *Supporting Indigenous researchers: A practical guide for supervisors* – available online at http://www.lowitja.org.au/lowitja-publishing/C023.

The literature review is attached at: G:\Research\Health\Lowitja_AIATSIS_ethics_evaluation\Lit review\Folder to send to NHMRC\International review.docx.

5. EVALUATION OBJECTIVES

The evaluation objectives were:

1. To find out how Human Research Ethics Committees (HRECs) have used the guidelines to undertake ethical review of Aboriginal and Torres Strait Islander health research;
2. To find out how researchers have used the guidelines to undertake ethical Aboriginal and Torres Strait Islander health research;
3. To find out from Aboriginal and Torres Strait Islander communities if the guidelines have been educative, improved skills and increased capacity in engaging with ethical research;
4. Consider other Australian and international documentation on this issue; and
5. Identify areas where improvements to the guidelines can be made.

6. EVALUATION AIMS:

The evaluation aims were:

- To make recommendations on how to improve the effectiveness of the guidelines through interrogating their practical application;
- To make recommendations regarding training, capacity building, further investigations and/or development of additional appropriate guiding materials;
- Maintain the contemporary nature of the guidelines through collection of suggested amendments, application, content and coverage issues for any review;
- Consider international approaches; and
- Highlight potential discrepancies between information contained in:
  - *The National Statement on Ethical Conduct in Research Involving Humans* (the *National Statement*);
  - *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research*;
  - *Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics*;
  - AIATSIS' *Guidelines for Ethical Research in Australian Indigenous Studies (GERAIS)*; and
  - The Aboriginal Health & Medical Research Council of NSW (AH&MRC).

7. EVALUATION OUTPUTS

This report provides the NHMRC with information about the experiences of stakeholders in using the guidelines. It also suggests areas for improvements and revisions. We also make recommendations concerning the development of additional materials and strategies to support the implementation of the guidelines.

The literature review contains information about inconsistencies with other advice, e.g. AIATSIS' *GERAIS*; and relevant international and other best practice approaches.

8. RESULTS

This section provides a brief overview of the stakeholder groups that attended the face-to-face consultations held across the 12 sites and feedback provided via surveys.

a. OVERVIEW OF CONSULTATIONS AND SURVEY FEEDBACK

Of the 300 people who attended the face-to-face consultations, 213 completed the relevant stakeholder survey. Every jurisdiction was represented in the consultations (Figure 1). Queensland had the greatest representation, reflecting the three consultation sites in Queensland (Brisbane, Cairns and Thursday Island).

FIGURE 1: PROPORTION OF SURVEY RESPONDENTS BY JURISDICTION
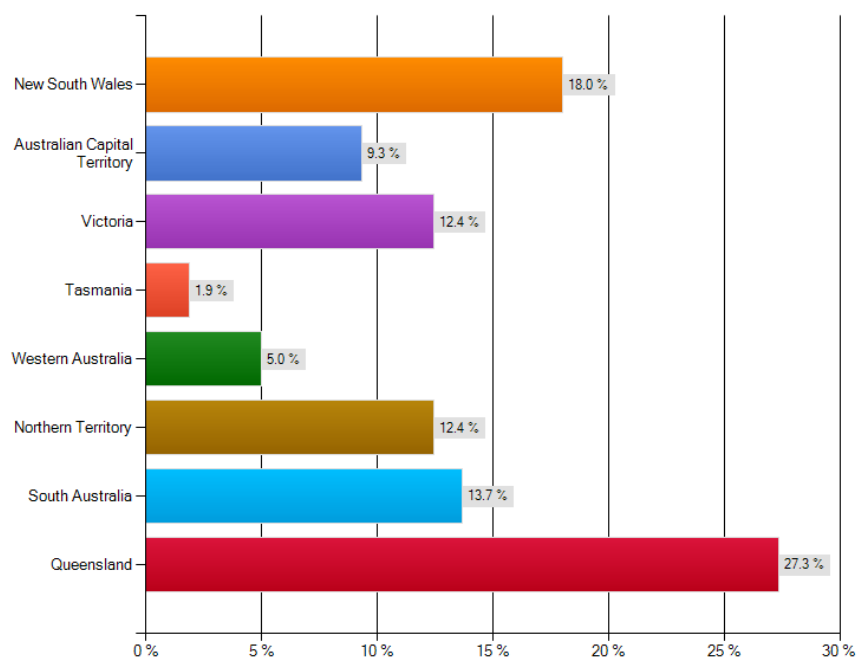
Of the survey respondents the least represented group were community organisations that participated in research and Aboriginal and Torres Strait Islander community members (although 40 per cent of researchers were Aboriginal and/or Torres Strait Islander and should also be considered community members). There was good representation from the academic sector and from ethics committees.

TABLE 1: PROPORTION AND COUNT OF SURVEY RESPONDENTS BY STAKEHOLDER CATEGORY

Stakeholder	%	n
An Aboriginal and or Torres Strait Islander community member	4.2%	9
A community organisation that conducts	5.2%	11

Stakeholder	%	n
research		
A HREC administrator	11.7%	25
A researcher	39.4%	84
An ethics committee member	16.9%	36
A research institution/organisation	6.1%	13
A community organisation that participates in research	2.3%	5
A Government agency	5.6%	12
A private organisation/consulting firm	2.3%	5
Other	6.1%	13
Total	100	213

9. THE DEGREE TO WHICH THE GUIDELINES HAVE BEEN EDUCATIVE, IMPROVED SKILLS AND INCREASED CAPACITY IN ENGAGING WITH ETHICAL RESEARCH AMONG ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES

This section presents the feedback from community stakeholders about *Values and Ethics* and *Keeping Research on Track* and suggestions for improvements.

a. IMPACT OF *VALUES AND ETHICS* AND *KEEPING RESEARCH ON TRACK* IN COMMUNITIES

The consultation identified that *Keeping Research on Track* is predominantly used by community, community based organisations and researchers. However, there are many that are not aware of it. For those that are aware, it is used to facilitate more meaningful engagement in the health research sector. While there continues to be limited awareness and distribution of *Keeping Research on Track* researchers were aware that it was a good tool and *'a more visual document to take to community'* . The use of *Keeping Research on Track* was now common practice at commencement of the process of research in communities.

b. WHO IN COMMUNITIES DO RESEARCHERS GO TO AND WHEN DO THEY NEED TO GO TO THEM?

'Much research is undertaken in true collaboration, but on the other hand ethics are sometimes seen as an infringement of academic freedom'

Researchers, community members, community organisations and ethics bodies discussed at many of the consultations, the *right process* in initiating contact with Aboriginal and Torres Strait Islander communities and the *right process* for attaining support for the research proposal. Similarly, there was detailed discussion about the right people and or organisations that had the right to speak on the communities' behalf. Negative examples included '*In the Northern Territory, people consult with the business manager in super shires (who don't have the authority to speak for communities)'*. Another example for north Queensland included a researcher going into a community to seek support for their PhD research. When the community leaders began questioning the research process, the researcher deliberately chose an '*Aunty*' who was more receptive to the researcher, then utilised the Aunty's ability to influence the elders and gain support for the research. In a similar vein some participants were aware that some Aboriginal and Torres Strait Islander people were being targeted in the research process of engagement and 'that one Aboriginal person may not have the necessary background/authority. It is important to engage with the most appropriate community person'. One suggestion for overcoming this approach included community based organisations and other governance structures such as Aboriginal Medical Services defining the terms of engagement e.g. Memorandum of Agreement between community organisations and universities.

Often due to the tight timeframes within institutional research organisations, community engagement, consultation and thus support for the research was identified as still being an afterthought. This notion was often encountered in the consultations. Stakeholders said that research proposals were usually so far developed that if communities and organisations had concerns about methods and methodologies 'there was limited scope to discuss or negotiate methods, because the application was due in a week'. Clearly a need exists to improve how early researchers are engaging the community. Suggestions for overcoming this included having community engagement as a funded component within research proposals.

c. COMMUNITY DISENGAGEMENT IN THE RESEARCH PROCESS

Much of the feedback from communities indicates a level of dismay and disengagement with the research process. It was reported that community can *'get fobbed off'*, particularly in relation to large, influential academic research institutions. *'The process is back to front – research ideas should come from the community'*. Communities also felt very strongly that research ideas are too often investigator-driven rather than community-driven, and that findings were too often presented from the researcher's perspective rather than that of community. Other significant concerns regarding community experience of the guidelines included:

- Researchers need to be more transparent and honest in order to build trust;
- Peak bodies can be overwhelmed with having to manage the volume of proposals;
- Issues around having to provide letters of support to researchers, with pressure to sign and insufficient time to properly consider;

Such disengagement with the research process points to a need for all stakeholders to strongly and genuinely engage in the ethics process, supported by robust ethics resources and training.

It was reported however that despite the difficulties encountered in the research process, communities did not want researchers and HRECs to see Aboriginal health research as too hard, rather that there are processes that can be followed that will improve the research quality and output.

d. OWNERSHIP AND AUTHORSHIP OF RESEARCH

The question of ownership and authorship was raised at a number of consultations. Many communities feel that they should co-own the data together with the researcher/research organisation. It can be said that ownership is implied in most of the values (reciprocity, respect, equality, responsibility). However, none of the values address question of ownership explicitly.

e. EXTERNAL MONITORING OF RESEARCH

At over half of the face-to-face consultations, community members and researchers wanted to better understand the role of HRECS in monitoring Aboriginal health research. The role of monitoring the research was seen by community members as vitally important because issues such as ongoing community consent of research often becomes an issue. Also the monitoring process was seen as a way for individuals and community to have some control over the continuation or discontinuation of research. As one participant stated: '*Lots of scrutiny happens at the front end; but what happens after the letter of support is given*?' As a way of bolstering this process, participants suggested HRECs develop as part of their monitoring processes, a function to monitor continued engagement, involvement and approval for the research project that would be including in the HREC monitoring process.

f. SUGGESTED IMPROVEMENT FOR COMMUNITY AND COMMUNITIES

The consultations highlighted the following to ensure greater awareness and use of *Keeping Research on Track* and in the research process:

- There is a need to ensure relevance of the two documents to the community, which might be achieved by:
    - Strategically promoting availability and awareness of the documents;
    - Offering multiple formats including language and media.
    - Use Aboriginal iconography to tell the story.
    - Use accompanying documents.
- There is a continuing need to explain the role of ethics committees for community:
    - Including the need for community to be protected and involved in the research process.
    - Communities have the right to say no and this needs further exploration.
    - Within the research process, there has to be a way to privilege Aboriginal and Torres Strait Islander knowledge and cultural practices as part of the ethics process.
- Empowerment in the research process requires building. A process to identify community based research priorities needs to be established and funded. This might include:

- Greater accountability and monitoring in the research proposal development phase
- A Community based health Research funding round

10. RESEARCHER USE OF THE GUIDELINES TO UNDERTAKE ETHICAL ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

This section presents feedback from researchers who took part in the stakeholder survey and consultations concerning how they have used both *Values and Ethics* and *Keeping Research on Track* and suggestions for improvements.

a. RESEARCHER PARTICIPANTS

There were 84 researchers who completed the stakeholder survey. A high proportion of researchers attended the consultations, and in the responses to the survey, 41 per cent were Aboriginal and Torres Strait Islander people (Figure 2). Most researchers had been in the research field for over a decade (mean researcher career length = 11.5 years). Aboriginal and Torres Strait Islander researchers, on average, had slightly shorter research careers of 10.5 years. There was a wide variation in researcher expertise (Figure 3), the majority though were from public health and health services research focus areas.

FIGURE 2: PROPORTION OF RESEARCHERS IDENTIFYING AS ABORIGINAL AND/OR TORRES STRAIT ISLANDER
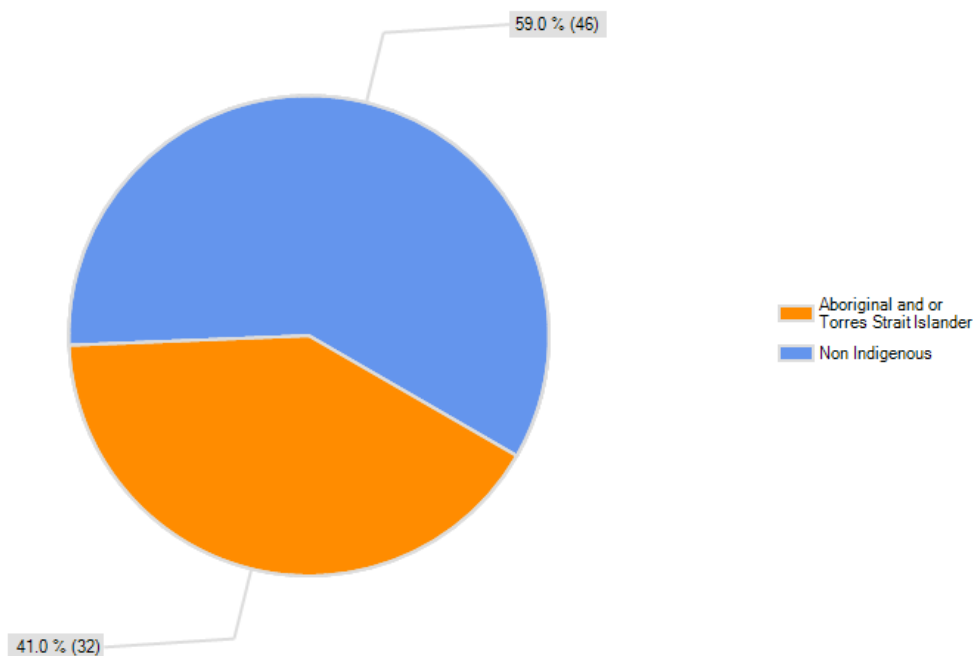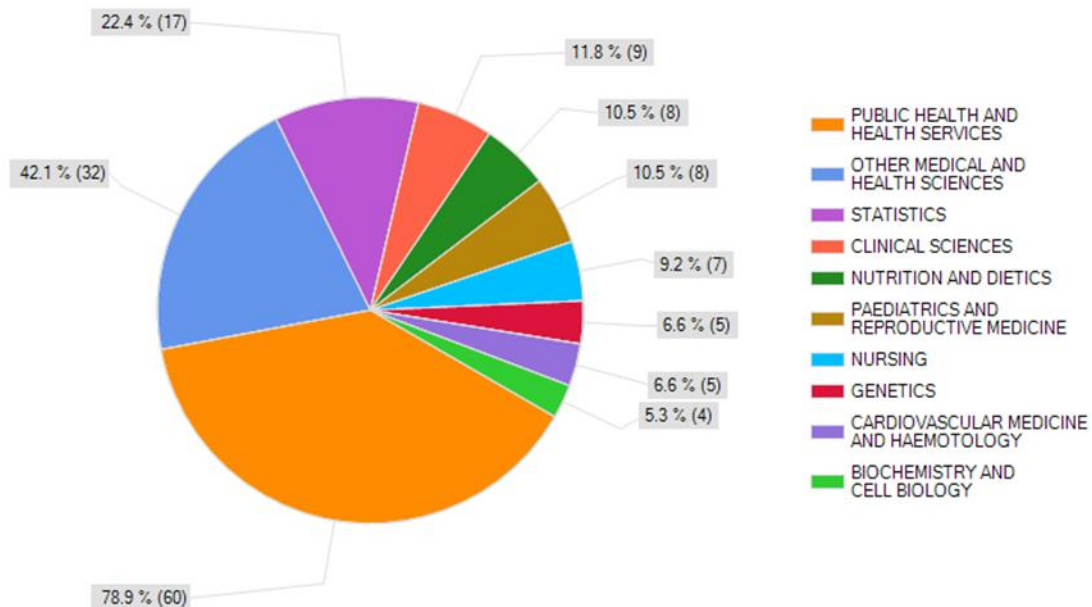
b. KNOWLEDGE AND USE OF THE DOCUMENTS

Data from the survey indicated that researchers generally found the *Values and Ethics* document useful (45.9 per cent strongly agree; 47.3 per cent agree). Over 80 per cent of researchers surveyed said that they refer to the guidelines for advice. 80 per cent of researchers said that the guidelines are easily understood. 40 per cent of researchers thought that the guidelies should be re-written and 40 per cent were not sure. 90 per cent of researchers agreed that there is a need for the guidelines.

Researchers surveyed said that *Keeping Research on Track* was useful (50 per cent strongly agreed; 32.4 per cent agreed). Almost 80 per cent of researchers refer to *Keeping Research on Track* for advice; 76 per cent agreed or strongly agreed that it is easy to understand; 40 per cent thought that it required revision and 45 per cent were unsure. 54 per cent of researchers were unsure if it should be written and 75 per cent agreed that there is a need for *Keeping Research on Track*.

c. RESEARCHER AND RESEARCH INSTITUTE CHALLENGES ASSOCIATED WITH ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

ONEROUS PROCESSES HOLDING BACK RESEARCH

A majority of researchers said that the *research process* was the most challenging component of research focused on Aboriginal and Torres Strait Islander health. For both Aboriginal and Torres

Strait Islander health researchers and non-Indigenous researchers the two greatest challenges identified were consultation and the additional time required to conduct research.

In the submissions, consultations and surveys, respondents spoke of how the additional requirements of addressing the values in *Values and Ethics* was responsible for marginalising Aboriginal and Torres Strait Islander people as research participants:

> *Incorporating ATSI [sic] people are too onerous for studies where the ethnicity of the participant is not the primary focus, hence the reason why they choose to exclude this population group in their study and that because of these requirements there is a real danger that out of respect for ATSI sensitivity, researchers are shying away from projects which could lead to research findings relevant to ATSI people.*

Researchers were also asking where the line was in '*ticking the box*' (where the values needed to be addressed) and '*What percentage of the population has to be made up of ATSI peoples*' before the box is ticked?'

Clearer guidance is required for both researchers and ethics committees on this. The way the AH&MRC address this issue may be useful for providing guidance in the revised documents where:

> *The AH&MRC guidelines require researchers and those wanting to use health information about Aboriginal people in NSW to seek ethical review from the AH&MRC Ethics Committee if one or more of the following criteria apply:*
>
> - *The experience of Aboriginal people is an explicit focus of all or part of the research; or*
>
> - *Data collection is explicitly directed at Aboriginal peoples; or*
>
> - *Aboriginal peoples, as a group, are to be examined in the results; or*
>
> - *The information has an impact on one or more Aboriginal communities; or*
>
> - *Aboriginal health funds are a source of funding*

Guidance to researchers and ethics committees could include similar advice. That is, if any of the above criteria apply, then they are required to address the Values in the revised *Values and Ethics* document.

DEVELOPING RESEARCH PRIORITIES FROM A BOTTOM UP APPROACH

It would appear that the focus in identifying and developing research projects still remains with the researchers and research institutes. This theme was recounted at every consultation and resonant with both community and researcher feedback.

In a number of submissions the role of consultation and engagement with community to identify research priorities was highlighted:

> *For the Lowitja Institute, it is important to keep building genuine partnerships between Aboriginal and Torres Strait Islander communities and organisations and researchers.*

Significantly, such partnerships need to be founded on the priorities and needs that the Aboriginal and Torres Strait Islander organisations and communities themselves identify: the key questions remain – what are they trying to do and how can research help them achieve their goals? This requires collaborative strategic goal setting, rather than basing research priority setting solely on conventional competitive grants processes where researchers identify what they believe are the research needs, and then subsequently in effect ask the community for permission to carry out the research thus identified.

d. TENSIONS BETWEEN ABORIGINAL AND TORRES STRAIT ISLANDER ACADEMICS AND ACADEMIC INSTITUTIONS

One of the major themes identified in the survey among Aboriginal and Torres Strait Islander academics was being compromised between (a) the intent of the values and (b) the pressure at the academic level for academic outcomes, as exemplified by:

While providing feedback to community, following guidelines and supporting capacity building sometimes the lead investigators change focus/delay outcomes/make promises they don't keep like researchers that do consultations with community/workers years later the process/findings to validate are not reported. Big researchers that may use and discard Indigenous people for their knowledge once researchers have what they think is important they discard knowledge base. As we live in community but we don't want to destroy trust with community/research. We say little but we become more wary.

Even when researchers provide feedback to communities there are some concerns with how data is interpreted and analysed: *'I think there is a strong need for research translation to be embedded into research design to ensure the voice of the community in directing what the findings mean. Indigenous epistemology should be integral in an Indigenous health research design'.* Contextualising what the data mean should be seen as enhancing the research process, but this is often seen as adding layers to an already time consuming process. Aboriginal and Torres Strait Islander academics described being caught in the middle: *'Aboriginal researchers are put in an awkward position when conducting research in our Aboriginal communities. Research protocols and academic needs almost always take precedence over community needs and outcomes, and the Aboriginal researcher is usually not in a position of power to correct this imbalance'.*

e. USE, UNDERSTANDING AND CONTEXT FOR RESEARCHERS

While many researchers believed both documents were needed, there was a clear recognition that they were underutilised or the research community were unaware of them. The reasons for this covered the ease of understanding the documents and a lack of guidance or assumptions about researchers intuitively knowing how to address the values. At the community level there was a clear recognition by researchers that dissemination and thus awareness of *Keeping Research on Track* was poor:

I think that both documents are underutilized by the groups they are intended to assist. Values and Ethics *is a good document, but not easily used. The AIATSIS*

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guidelines offer a better ... for researchers. It does not provide answers to some typical dilemmas research and ethics committees face. These should be included (e.g. as scenarios). It should be updated with a list of resources. Keeping Research on Track *is an excellent document but needs to be actively promoted within communities/community organizations in order to build the capacity for locally led research. The document on its own is not enough.*

UNDERSTANDING THE VALUES AND APPLYING THEM

A theme recurring throughout the consultations was a lack of conceptualising the values into actions undertaken in the research process: '*While the six key values and ethics for Aboriginal and Torres Strait Islander health research provide a culturally respectful framework for conducting research, they may be improved by emphasising how these principles are implemented in practice'.* In dealing with a lack of understanding it was suggested:

> *One way a revised version of the NHMRC document 'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research', could help with this issue is to provide exemplars to support the translation of the six values and ethics outlined in the guidelines: reciprocity, respect, equality, responsibility, survival and protection, spirit and integrity.*

DEMONSTRATING COMPLIANCE WITH THE VALUES

Researchers also recognised problems in the monitoring process:

> *the guidelines should have ongoing oversight and adherence to them should be a condition of funding. If guidelines are just guidelines, as is oft stated, there is no requirement to honour them. Forget about the spirit and integrity, value and respect, if they remain guidelines with no ongoing oversight or formal funding requirement. The guidelines should be a formal part of any funding arrangements, and oversight should be provided to ensure they are not tokenistic.*

Most of the suggestions around how to improve this matter were to ensure better ethics monitoring, particularly annual reports, including more information on how community engagement was maintained throughout the reporting period and processes to demonstrate continued community support for the research project.

f. MOVING THE SIX VALUES INTO THE *NATIONAL STATEMENT*?

Many researchers (as well as community members and some ethics committee participants) stated a preference for the six values outlined in the *Values and Ethics* to be incorporated into the *National Statement* as they were universal across a *'multi-cultural society that should be considered in the National Statement by all population groups?'* Both the *National Statement* and *Values and Ethics* contain Respect as a value, but as highlighted in the inconsistencies section of this document, both might mean different things when they are addressed in the ethics application.

g. SUGGESTED IMPROVEMENTS FOR RESEARCHER USE

- Greater promotion of the revised documents is essential if we are to improve knowledge of them and to increase uptake in use of them in the research process.

- Orientation and training should be available for researchers and research organisations to attain an acceptable level of cultural competence, particularly for those who are new to the sector. Training should cover community protocols and Aboriginal and Torres Strait Islander history which then provides a rationale for ethics.
- Monitoring of research projects in Aboriginal and Torres Strait Islander health research needs to be enhanced to ensure that researchers and their institutions follow the guidelines and can demonstrate continued support for research projects.
- The current documents could be improved by adding a series of case studies presented as Aboriginal stories, in keeping with cultural practice, to provide readers with a real application of the values in health research. Inclusion of scenarios or examples of good practice in addressing the Values would demonstrate how researchers and academic institutions might address these values.
- A central point for Aboriginal and Torres Strait Islander health research advice and referral is required.
- The Coverage Section in the 'Value and Ethics Guidelines' states that the guidelines have the same status and authority as the 'National Statement on Ethical Conduct in Human Research 2007' (*National Statement*). The same wording should be reflected in both documents to avoid any confusion around authority.
- Consideration be given to reflecting the values articulated in *Values and Ethics* into the *National Statement.*

11. HUMAN RESEARCH ETHICS COMMITTEES (HRECS) ETHICAL REVIEW OF ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

This section presents feedback from ethics committees and their members who took part in the stakeholder survey and consultations. It contains information about how *Values and Ethics* is used by HRECS in assessing ethics applications and suggestions for improvements.

a. HRECS AND THEIR MEMBERSHIP

There was good representation by HREC members in the consultations and in survey responses (n=34). Of those responding to the survey just over one quarter [26 per cent (n=8)] were Aboriginal or Torres Strait Islander members of HRECs. Figure 4 shows the range of HREC members that completed the survey. The mean time that a member had been involved in assessing ethics applications was 6.9 years, with Aboriginal and Torres Strait Islander committee members having slightly less experience at 5.6 years compared to 7.3 years for non-Indigenous committee members.
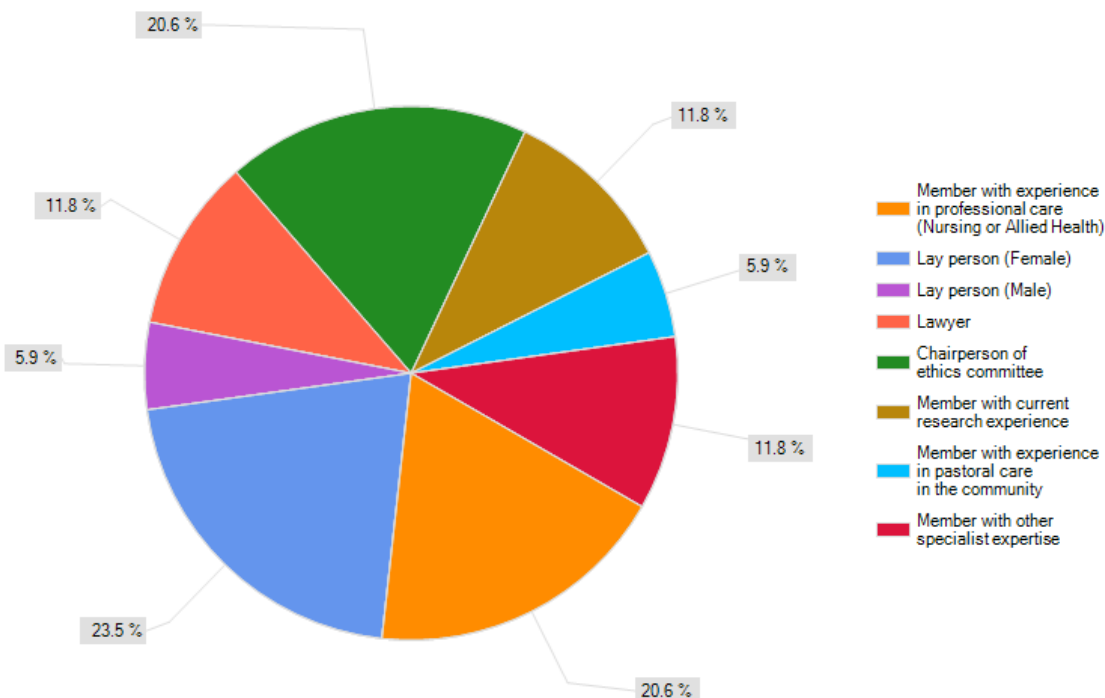
b. KNOWLEDGE OF AND USE OF THE DOCUMENTS

Three of the 34 ethics committee members had not heard of the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research document* and almost 20 per cent had not heard of the 'Keeping Research on Track document.

Most ethics committee members stated they were aware of *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research*, but were unfamiliar with the document content. A recurring theme from the consultations centred on ethics committee members being aware of both documents, but they '*did not receive either document when they joined the committee'*. Therefore awareness of both documents was good, but understanding and use of the documents in assessing application was limited. Ethics committee participants also expressed the view that ethics committees were not routinely using *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research* when assessing Aboriginal and Torre strait islander health research.

Like other stakeholders, ethics committee members wanted both documents shortened in length and better use of plain language. This was particularly the case for the 'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research'.

The consultations identified a tension between which documents (the *National Statement* or *Values and Ethics*) took precedence in the ethics assessment process and when ethics applications required the six additional values to be applied. Ethics committee members wanted clarification around when they were required to apply the six values from 'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research'.

The majority of ethics committee member's survey respondents said the guidelines were useful and an overwhelming majority said they were required. However, almost a quarter of respondents did not refer to the guidelines for advice and just over 30 per cent said they did require revision (See Figure 5).

FIGURE 5: ETHICS COMMITTEE MEMBER OPINION OF VALUES AND ETHICS: GUIDELINES FOR ETHICAL CONDUCT IN ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH IN ASSESSING RESEARCH PROPOSALS
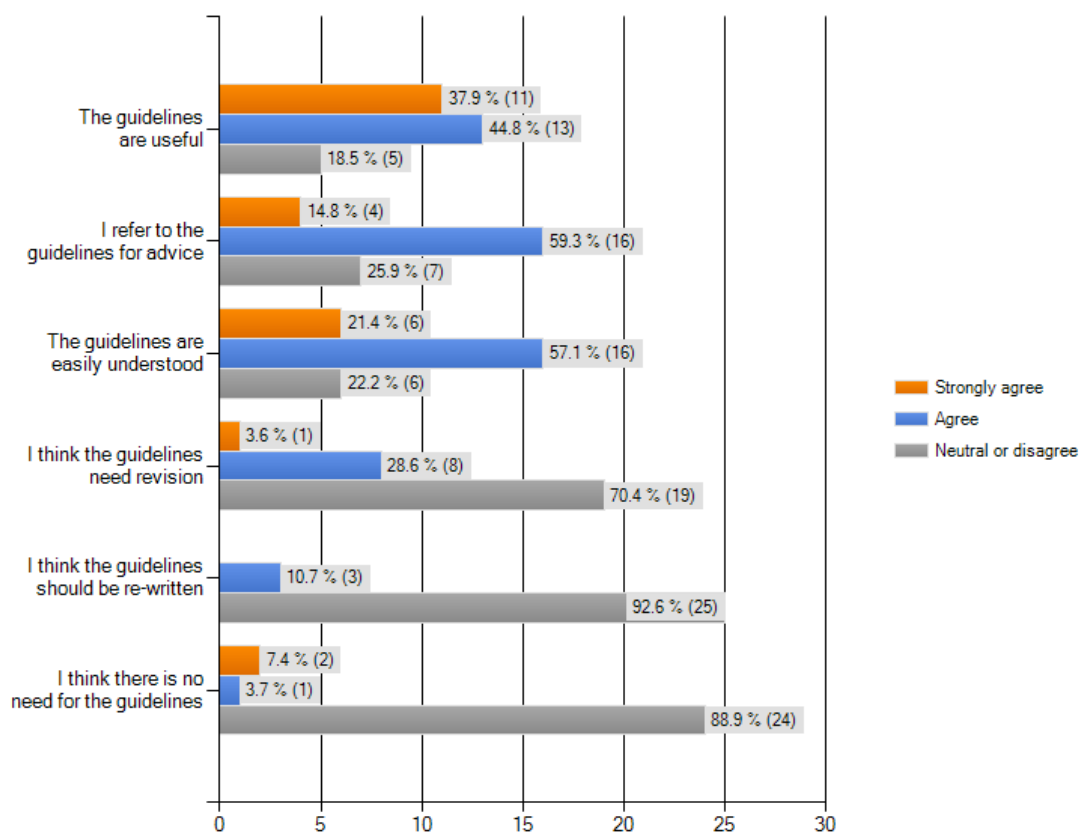
Drilling down further into the values and committee member confidence in assessing these values showed that HRECs and their members wanted greater clarity on how the values translated to research practice and demonstrated tasks and processes they could see when an application was addressing each value. People commented that the values were '*too abstract'* and wanted clear examples of what applicants could do to address the value.

Overwhelmingly (over 75 per cent) of ethics committee members felt confident or mostly confident in assessing each Value (See Figure 6).

c. Ethics committee assessment of Aboriginal and Torres Strait Islander Health Research

Common practice for assessment of Aboriginal and Torres Strait Islander health research proposals was consistent and included forwarding the proposal to the ethics committee member with Aboriginal and Torres Strait Islander health research experience (Table 2). The review task predominantly fell to an Aboriginal and/or Torres Strait Islander person who was a member of the committee or a person with Aboriginal and Torres Strait Islander health research experience. Twenty nine per cent of committee members were unsure or unable to describe their committee's process for assessing Aboriginal and Torres Strait Islander health research proposals.

The review processes were highly dependent on the type of HREC. Some committees focused on different elements of health research – such as clinical trials (where there were few research proposal focused towards Aboriginal and Torres Strait Islander health) compared to social health research which had greater focus on Aboriginal and Torres Strait Islander health research. Across the different committees the use and application of the 'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research' were different depending on the focus of the committee.

d. THE HRECS ROLE IN MONITORING

At over half of the face-to-face consultations, community members and researchers wanted to better understand the role of HRECS in monitoring Aboriginal health research. The role of monitoring the research was seen by community members as vitally important because issues such as ongoing community consent of research often becomes an issue. Also the monitoring process was seen as a way for individuals and community to have some control over the continuation or discontinuation of research. As one participant contended: *'Lots of scrutiny happens at the front end; but what happens after the letter of support is given?'* As a way of enhancing this process participants suggested HRECs develop as part of their monitoring processes, a function to monitor continued engagement, involvement and approval for the research project that would be including in the HREC monitoring process.

e. CONFLATION OF RESEARCH TOPIC AND PARTICIPANTS

The consultations also highlighted a discrepancy between conceptualisation of the research – in terms of researching the illness and the participants of research. Many researchers and ethics committees look to the investigation of the drug, illness or processes of both, rather than who might be involved. An example of this tension was explained:

> *Some projects we see involve Aboriginal and Torres Strait Islander people by chance. i.e. the focus is on an illness and recruitment depends on the cohort presenting with the illness. This might mean that few, if any, people of Indigenous origin will be recruited. However, we would expect advice to be taken from hospital or local ATSI liaison officers or community advisers in considering the types of studies we generally use.*

Further examples were given by a number of participants during the consultations where researchers described that because the focus of the research was on the illness process, they therefore did not have to address the six Values in their ethics application. Another example centred on hospital acquired infections. The researchers believed they did not have to address the six values because: *'the research concerned hospital acquired infections, it just happened to be the case that those hospitals were based in remote communities with predominantly Aboriginal populations'*. The recruitment of Aboriginal people was rationalised as 'incidental' within the application. It was clear in this example and the others described that researchers were rationalising their approach so they avoided addressing the values, or were seeking ways to avoid community consultation.

Similar feedback was received about areas other than health:

> The Keeping Research on Track *document is an excellent outline that should apply across the board in research but it tends to be avoided by social sciences and behavioural sciences and especially education. I have witnessed some really amazing moves to avoid ethical clearance especially in education and social and emotional well-being areas where some Faculties have developed non-threatening research definitions to avoid the human ethics research committee processes.*

TABLE 2: HREC PROCESS FOR ASSESSING RESEARCH INVOLVING ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE.

Process	% (n)*
Aboriginal and or Torres Strait Islander person or person with relevant expertise	42 (13)
Against the 6 values	29 (9)
No process described	29 (9)
National Statement	19 (6)
Other	10 (3)

* Respondents could indicate more than one process

f. CAPACITY BUILDING OF ETHICS COMMITTEES

While HREC survey respondents indicated confidence in assessing the Values, many HREC members (in the consultations and in the survey) expressed a strong desire to have training in assessing ethics application using the values in 'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research'. Almost 70 per cent of survey participants indicated they had no training in Aboriginal and Torres Strait Islander Health research with 80 per cent indicating they would benefit from such training. The need for HRECs to be trained in assessing the values was also urged by community people.

g. SUGGESTED IMPROVEMENTS CONCERNING HRECS

A suggested improvement concerning HRECS is a program of work to raise awareness about the guidelines and to develop cultural competence of HRECs. This program of work should include the following elements:

- A strategic promotion and distribution of revised documents to NHMRC approved ethics committees;
- A training scheme to be developed and delivered for all approved ethics committees and members to ensure:
    - Committee members are familiar with the documents and specifically the Values,
    - Know when to consider them in research proposals; and
    - Are confident in assessing whether researchers are addressing the values appropriately
    - Conflation of research topic and research participant is limited; and
    - All HREC committee members are culturally competent to oversee the ethics process for Aboriginal and Torres Strait Islander health research work.
- A function to monitor continued engagement, involvement and approval for the research project in the HREC annual reports where Aboriginal and Torres Strait Islander health research is being conducted.

- Develop electronic resources for committees and their membership to use for continued development of their capacity to assess Aboriginal and Torres Strait Islander health research, that includes:
  o An orientation package for new committee members.
  o Examples of research where the Values are addressed well.
  o A checklist of what committee members should expect in Aboriginal and Torres Strait Islander health research from the front end (community engagement) to the final stages of research (feedback).
  o Information (updated on a regular basis) that drills down to the local and regional level (e.g. Torres Strait cultural protocols, or Aboriginal Medical Services Alliance Northern Territory Research Policy).
  o If HRECs do not have expertise represented on their current committee they engage with local Aboriginal and Torres Strait Islander communities and groups to bring in expertise when they need it in assessing research applications, This expertise could be attained from a number of sources, including:
    ▪ Local Aboriginal health services and their affiliates including the National Aboriginal Community Controlled Health Organisation (NACCHO).
    ▪ Universities.
    ▪ Aboriginal and Torres Strait Islander academic networks (NIRAKN).
    ▪ Aboriginal and Torres Strait Islander Health units within State and Territory Government departments and their regions.
- For those jurisdictions without Aboriginal community based ethics committees, these be established (Queensland, Tasmania).
- There is a proliferation of evaluations occurring in the Aboriginal health sector and these can often lead to new knowledge but they are exempt from the ethics process.
- Commit funding to print resources and to get them out to the places where they are needed and alternative methods are needed. E.g. DVD and other mediums.

h. HOW ETHICS COMMITTEES ARE USING *KEEPING RESEARCH ON TRACK*

When committee members were asked about how they were using *Keeping Research on Track*, most explained they were not aware of it. This is understandable as *'This document is aimed at empowering indigenous participants and researchers. The questions posed are very useful for interrogating the research'* as one of the ethics committee respondents described. For those who were aware of *Keeping Research on Track* this document was used as a way of building on their understanding of the concepts in the 'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research'. One respondent who encapsulated this notion in one of their comments said they '*Mainly use it as a reference additional to the values document. I use the values document as the main guideline'*.

12. INCONSISTENCIES BETWEEN THE AUSTRALIAN DOCUMENTS

a. DIFFERENCES IN BACKGROUND AND RATIONALE FOR GUIDELINES

The different documents base their reasoning for the principles and the need for ethical guidelines on varying backgrounds. *Values and Ethics* , *Keeping Research on Track* and the AH&MRC guidelines are created as a response to a history of damaging unethical practices of research being conducted on Aboriginal and Torres Strait Islander people, with almost no benefits for the local communities [2, 3]. These three guidelines are developed to *prevent* these unethical practices in health research involving Aboriginal and Torres Strait Islanders. On the contrary, Jamieson et al [12] take a more positive approach, in which they aim to *promote* ethical practices in research among Aboriginal populations by describing principles based on best practice from their own experience and what is extensively described in the literature. The AIATSIS guidelines take a different approach altogether and are based on a human rights framework. The United Nations Declaration on the Rights of Indigenous people [7] is the base for this framework and it is described what rights Aboriginal and Torres Strait Islander people have and how this should be applied in research [4]. Finally, the NHMRC *National Statement* starts from more general 'western' concepts of ethical research, reflected in the four principles of research merit and integrity, respect, beneficence and justice and applies these principles to Aboriginal and Torres Strait Islander research.

b. DIFFERENCES IN PRINCIPLES

These different approaches lead to a different focus in the principles. All of the guidelines discuss the importance of community engagement and involvement, agreements, equal and fair distribution of benefits and burden of the research, the need for respect for the distinctiveness of Aboriginal and Torres Strait Islander cultures and the importance of consent. However, where *Values and Ethics* emphasizes community engagement and involvement in every aspect of the research, it does not go as far as to discuss community control and ownership of every aspect of the research. This is done in the AH&MRC and AIATSIS guidelines and the 10 principles discussed by Jamieson et. al [4, 12, 13]. A simple search for the words 'ownership' and 'control', in the *Values and Ethics* document, results in no matches in the actual discussion of the principles. The AH&MRC guidelines highlights the importance of community control. Ensuring community control and ownership are central to these guidelines. This also becomes clear from the emphasis on letting the community decide on the research and the AH&MRC ethics committee positioning itself as an advisory organ [13]. Based on the Human rights of self-determination, the AIATSIS guidelines also emphasize the importance of community ownership and the rights of communities to control research that is conducted in their communities. Jamieson et. al [12] also emphasize that research shows that projects are most accepted, effective and sustainable when there are high levels of community ownership and control over the project. Based on this observation it might be fair to say that the *Values and Ethics* guidelines are too conservative in their position regarding community involvement, ownership and control.

In line with these observations made considering community control, is the observation that the AIATSIS and AH&MRC guidelines and the Jamieson paper discuss that research should be responding to the needs of the local community, determined by the local community. This 'bottom up' approach

is in contrast with the 'top down' approach described in the three NHMRC guidelines, in which there is no mention of communities deciding the research agenda, but is only discussed that research should be appropriate for the community, should not harm the community and should 'advance the interest of Aboriginal and Torres Strait Islander Peoples' [1]. Again, the NHMRC guidelines are more conservative on the issue of allowing communities to control the research.

The AH&MRC guidelines are strong on the issue that only communities themselves can approve what research is going on in their communities. On the other hand the NHMRC *National Statement* states that it is enough to have someone who is familiar with the culture and practices of Aboriginal and Torres Strait Islanders, or someone that has networks with Aboriginal and/or Torres Strait Islanders and is familiar with the research practices. So the HRECs, according to the *National Statement*, do not even have to ask advice, nor include an Aboriginal and/or Torres Strait Islander person. But for the AH&MRC guidelines this community involvement is essential.

Even though *Values and Ethics* and the NHMRC *National Statement* are closely related and they both refer to each other, there are discrepancies in their wording of the principles and where they place certain important aspects of Aboriginal health research. This can be slightly confusing as they discuss the same principles, but give them different names or the same names, such as 'respect'. Both documents discuss respect, but they do not cover the same areas. For example, *Values and Ethics* include the assessment of risks and benefits in the principle of respect, but in the *National Statement* this is placed in 'Beneficence'. 'Integrity' in the *National Statement* means a commitment to development of understanding and knowledge, based on rigorous research methods. However, 'integrity' in *Values and Ethics* is about the maintenance and coherence of past, present and future Aboriginal and Torres Strait Islander values and cultures.

c. TARGET GROUP

It is clear from the language used in *Keeping Research on Track* that it is developed for communities. It gives clear direction on what the community can and should do in every step of the research. This document clearly shows that Aboriginal people and community do not have to be passive participants, but they can be actively involved in research and determine the research conducted on their lands and communities. This differs from the other guidelines, because the other guidelines, such as the AIATSIS' *GERAIS*, *Value and Ethics* and AH&MRC guidelines all focus on what the researcher should do to ensure research is conducted in a correct way.

d. PHILOSOPHICAL VERSUS PRAGMATIC

There is a difference in the level on which the different documents are written. *Keeping Research on Track*, AH&MRC guidelines and the ten principles by Jamieson et al are pragmatically written, whereas the NHMRC *National Statement*, *Values and Ethics* and the AIATSIS *GERAIS* are more philosophical and discuss the principles in more detail. The other documents place more emphasis on practical application of ethical principles. *Keeping Research on Track* is highly pragmatic by including a clear step-by-step research guide, in which the tasks of the researchers and the involvement of the communities are outlined in every step. The AH&MRC guidelines are more pragmatic because they outline when community consent is needed. This is missing in the *Values*

and Ethics document. Additionally they give practical examples of equal distribution of burden (reimbursing costs) and benefits (enhancing skills in the community through training).

The more philosophical nature of *Values and Ethics*, AIATSIS' *GERAIS* and NHMRC *National Statement* is also illustrated by the extensive summary given on the background of the guidelines. *Values and Ethics* dedicates nine pages to describing the historical and philosophical background of the guidelines and the development of the guidelines. The AIATSIS guidelines and the NHMRC *National Statement* do the same but have shorter introductions. One fault all three documents have when describing the application of the guidelines is that they miss practical examples of how to actually do that and tend to use more vague words such as 'ensure', 'discuss', 'be aware' and 'understand'.

e. DIFFERENCES IN WORD USE AND LAY OUT

In line with *Values and Ethics* being more philosophical, this document is also wordier than any of the other documents. The wording is complex and not easy to understand when first reading it. *Keeping Research on Track* is much easier to read and has a more attractive layout, with its use of a colourful background, less text on a page and bigger font size. Wording is simpler and concepts are explained in an easier and more straightforward manner. The AH&MRC guidelines are also shorter, more to the point with less elaborate explanations of the different principles. Paragraphs are short and use a lot of dot points, which makes the document clear and well-organized. The AIATSIS guidelines also work with listings of how to apply the principles and works with commands, which gives it an easy flow to read.

f. OTHER DIFFERENCES

Values and Ethics refers to the *National Statement*, but the paragraphs mentioned do not align anymore with the updated *National Statement*.

13. ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH ETHICS LANDSCAPE – A NATIONAL AND INTERNATIONAL REVIEW

The literature review is covered in a separate document entitled

RESEARCHING RIGHT WAY - ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH ETHICS: A DOMESTIC AND INTERNATIONAL REVIEW - OCTOBER 2013

14. CASE STUDIES OF GOOD PRACTICE IN ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

This literature search aimed to find published peer-reviewed papers that explicitly mentioned the use of and/or adherence to the ethical guidelines. Accordingly, a database search was conducted in Scopus using the following search string: TITLE-ABS-KEY ("values and ethics ") OR ("keeping research on track") AND ("Aboriginal" OR "Torres Strait" OR "Indigenous") AND "Australia". This search resulted in 28 hits. Results were consequently scanned on whether the publication described new research. Discussion papers were excluded. Only papers that were published after 2003 were included, because *Values and Ethics* was published this year. The search identified nine papers eligible for inclusion. An additional strategy was browsing the 'research ethics' section on the Australian Indigenous Health*InfoNet* website.

This section provides an overview of guidelines and organisations on Aboriginal and Torres Strait Islander research ethics and it also has a list of publications addressing ethics related to Aboriginal and Torres Strait Islander research.[2] The same selection process was used for the Scopus papers. Five papers were found eligible, however four of them had already been identified through the Scopus search. Thus only one additional paper was found in the Health*InfoNet* database. One additional paper was obtained after a tip from an expert in the field who attended one of the consultations. Two other papers were identified from a reference list of another publication. A total of thirteen papers describing the application of ethical guidelines in their research were identified and are described below. Each publication describes the research aims and how each addressed the six central values of *Values and Ethics.* The results are presented as case studies at the conclusion of the Literature Review (attached).

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[2] http://www.healthinfonet.ecu.edu.au/health-infrastructure/ethics/publications/specific-topics/research-ethics

15.   OTHER ISSUES RAISED

The consultations raised a number of issues that are out of scope of this evaluation, but are closely related to the need for ethics documents and ethics processes, and therefore important to report back to the NHMRC.

There is a need for clearer processes in relation to Aboriginal and Torres Strait Islander health research. Workshop participants reported that many people struggle to understand the ethics process – from both the research and the community perspective. There was a call for a much more robust framework to support the ethics processes. Inconsistency of Aboriginal ethics committees across jurisdictions creates confusion and impedes confidence in the ethics process. Many participants called for the need to standardise and simplify the process, and to reinforce with tools (e.g. templates, checklists) to support accountability. There was recurrent feedback around uncertainty as to when and how to use ethics guidelines, and which guidelines to use e.g. – (a) *National Statement*; (b) *Values and Ethics* and/or *Keeping Research on Track*; AIATSIS' *GERAIS*; AH&MRC guidelines or other jurisdictional guidelines.

Workshops participants often talked about the tensions that arise in research. These tensions include the conflict between pressure from funders to deliver an outcome versus expectations from community for research to be done in a consultative, inclusive and respectful manner. It includes the fact that the project timeline does not always allow proper community planning and consultation or capacity building is not always built into the research project.

Feedback strongly indicated an insufficient regard for the ethics process for Aboriginal and Torres Strait Islander health research projects.   Workshop participants reported that community consultation is often 'tokenistic'. Not all researchers engage with the guidelines when undertaking research. One consultation reported that commitment to the Aboriginal and Torres Strait Islander ethics process was 'an infringement of their academic rights'. At more than one consultation, it was reported that ethics is seen as an imposition, that it makes research too hard or as adding to an already onerous process. The matter of authority being sought from inappropriate community contacts creates a high level of mistrust of research and researchers.

A number of consultations spoke about the imbalance of power in the research process. Significant non-Aboriginal academic institutions in particular were perceived to have a disregard for the need to listen and to work in genuine partnership with communities.

There is a need to raise awareness amongst communities that Aboriginal and Torres Strait Islander people have rights in the research process and should be empowered to question, to participate, and to have input into research projects that affect their health and their lives, throughout the entire process.

Many people also expressed concern about evaluations that occur within community projects and suggested that evaluations should also be scrutinized through an ethics process.

16.   NEW AND EMERGING ISSUES

There is a level of anxiety on the part of community regarding new health research technologies. Historically, many Aboriginal and Torres Strait Islander communities have been deeply suspicious of research in general. Unfortunately, this anxiety can be further exacerbated in relation to new scientific technologies.

The current documents are not sufficient to address emerging technologies such as genetic/genomic science, epigenetics, stem cell research and psych-testing.   There are considerations also around data-linkage and identification issues. Other issues raised included:

- How to address research that is not principally targeted at Aboriginal and Torres Strait Islander people, but a significant proportion of Aboriginal people say 25% of the study.
- How to apply the values to people working on Aboriginal and Torres Strait Islander tissue in laboratories.
- Protocols around historically collected material – especially when samples have been taken.

Given that there are benefits of new technologies, as well as risks, there is a need for awareness, understanding and open discussion about these issues so that Aboriginal and Torres Strait Islander people can make better-informed decisions regarding participation in such research. In addition, the research community should be educated and aware of the basis of caution on the part of Aboriginal communities.

APPENDIX 1: CONSULTATION SCHEDULE

TABLE 3 : EVALUATION CONSULTATION SCHEDULE BY DATE, LOCATION AND VENUE AND ATTENDANCE

Location	Venue	Staff	RSVPs	Attendance
Canberra	Tuesday 2 July, Mabo Room: AIATSIS, Lawson Crescent, Acton Peninsula	Ray Lovett Mary Guthrie Ngaire Brown Ruth Gilbert	36	40
Melbourne	Thursday 4 July, Conference room, Victorian Aboriginal Health Service (VAHS) Preston Office 238–250 Plenty Road, Preston	Ray Lovett Mary Guthrie Professor Kerry Arabena	40	33
Sydney	Monday 15 July, Conference room, National Centre for Indigenous Excellence, 180 George Street, Redfern, Sydney	Ray Lovett Mary Guthrie Kerry Arabena	32	30
Hobart	Thursday 18 July, Riuwunna Centre, University of Tasmania, Churchill Avenue, Sandy Bay	Mary Guthrie Kerry Arabena	5	6
Broome	Monday 5 August, Jimmy Chi Hall, Broome Civic Centre, 27 Weld Street, Broome	Mary Guthrie Professor Bronwyn Fredericks	10	12
Thursday Island	Monday 5 August, Port Kennedy Hall, 64-66 Douglas Street, Thursday Island	Ray Lovett Associate Professor Mark Wenitong	4	6
Brisbane	Wednesday 7 August, Conference room, ATSICHS Head office, 55 Annerley Road, Woolloongabba	Ray Lovett Professor Bronwyn Fredericks Ruth Gilbert	46	36
Perth	Wednesday 7 August, Conference room, Derbarl Yerrigan, 156 Wittenoom Street, East Perth	Mary Guthrie Alwin Chong		22
Adelaide	Monday 12 August, Functions	Mary Guthrie	40	28

Location	Venue	Staff	RSVPs	Attendance
	Hall, Nunkuwarrin Yunti, 182–190 Wakefield Street, Adelaide	Alwin Chong Ruth Gilbert		
Darwin	Monday 12 August, Room 6.1.03, Casuarina Campus, Charles Darwin University, Ellengowan Drive, Casuarina	Ray Lovett Professor Ngaire Brown	12	13
Cairns	Wednesday 14 August, Conference room, Wuchopperen Health Services, 13 Moignard Street, Manoora, Cairns -	Ray Lovett Associate Professor Mark Wenitong	15	12
Alice Springs	Thursday 15 August, Corkwood Room, Desert Knowledge Australia, Desert Knowledge Precinct, South Stuart Highway, Alice Springs	Mary Guthrie Professor Ngaire Brown	18	15

1. Mt Isa Centre for Rural and Remote Health

2. Dr Ruth Nicholls, ACT

3. Anton Isaacs, Monash University Department of Rural and Indigenous Health

4. Ms Clair Anderson, University of Tasmania

5. The Lowitja Institute

6. Aboriginal Health and Medical Research Council of New South Wales (AHMRC)

7. Queensland Health Forensic and Scientific Services

Human Ethics Committee (FSS-HEC)

8.Royal Australian and New Zealand College of Psychiatrists

'Researching Right Way' Alice Springs consultation notes

Stakeholder Experiences of using the NHMRC guidelines *Values and Ethics* and *Keeping Research on Track.*

- Lack of awareness of both documents
- Issue regarding availability of documents – because document no longer printed there is a cost shift from government to the user (including communities) – thereby limiting access.
- *Keeping Research on Track* and *Values & Ethics* must be living documents – currently incongruous with the priority of NHMRC, ie. limited access; limited dissemination.
- *Keeping Research on Track* a more visual document to take to community.
- *Values and Ethics* is cumbersome to read.
- Case studies would be useful to exemplify, articulate the content, principles, etc.
- There is a need to ensure relevance of the two documents to the community:
    - Offer multiple formats including language, media, diversity.
    - Use Aboriginal iconography to tell the story.
    - Use accompanying documents.
- People struggle to make sense of them and how to apply them to projects;
    - A need for much more information about the ethics process – where to start. It really needs to include a checklist.
- How many researchers are confident and competent to go through this process?
- To what extent are the documents utilised by researchers?
- Need to rationalise / standardise some ethics processes.
- Need to explain the role of ethics committees for community:
    - Including the need for community to be protected in the research process.
    - Communities have the right to say no and this needs further exploration.
- We must privilege Aboriginal and Torres Strait Islander knowledge and cultural practices as part of the ethics process.
- Onus is placed on the participant – there needs to be a process where the onus is placed on the researcher, not the participant.
- Does the organisation have a quality assurance process in ethics.
- Who has the authority/mandate to give permission and/or speak on behalf of communities?

- In the Northern Territory, people consult with the business manager in super shires (who don't have the authority to speak for communities).
- How do you apply the principles to people working in laboratories?
- The current documents are not sufficient to address emerging and progressive 'science' – eg genetic/genomic; data linkage; epigenetics / DNA:
  - There is anxiety re this new science. The two documents don't help people deal with emerging science.
- Tension around the carrot ($) – stick (ethics).
- Need a template for communities to assist in the decision-making in the ethics process.
- Need strategies and resources for capacity building.
- Leadership - Aboriginal influence and practices (i.e. the right way to research) can improve the entire sector.
- Need to increase opportunities for diverse participation and contribution including Aboriginal researchers, cultural educators/advisors.
- Reciprocity – nature of reciprocity can be negotiation as well as feeding back findings etc. to community. It can also be something physical, such as a fridge for the bush clinic; a washing machine that community could use, etc. This might be more sustainable that a $50 voucher.
- Budgets don't often allow for capacity development.
- The benefit to community is often not well documented – this requires further explanation.
- Ethics process should reflect enough time to consult properly.
- Do not forget, overlook or diminish the history of research practice in Aboriginal communities, and the impacts of that practice.
- Letters of support from communities– consider a 'provisional' letter of support.
- Inconsistency of Aboriginal ethics committees across Australia – these differences need to be considered and addressed.
- Make more use of bringing in, or referring to, particular expertise. Some committees do this.
- Role of committees should be educative and not just put up barriers:
  - Best practice – provide constructive and critical feedback.

'Researching Right Way' Adelaide consultation notes:

Stakeholder experiences of using the guidelines *Keeping Research on Track* and *Values and Ethics.*

- Needs for much more info about ethics including a checklist, and a process defining where to start would be useful.
- Many participants found the documents *Keeping Research on Track* and *Values and Ethics* useful.
- Guidelines should be used earlier in the process by supervisors and student researchers to develop their research projects.
- Guidelines need to be respected by researchers.
- Document needs to address 'chicken and egg' dilemma – engaging with community is not an ethics process, but should be done ethically.
- Much research is undertaken in true collaboration, but on the other hand ethics are sometimes seen as an infringement of academic freedom.
- *Values and Ethics* is not user friendly; the content is good but it is difficult to read. *Keeping Research on Track* is easier to read.
- Not everyone is familiar with the documents, or aware of them; the committees aren't using them.

Enablers

- The guidelines themselves are enabling.
- Membership of HRECs is enabling.
- Incorporate *Values and Ethics* and *Keeping Research on Track* into the National Statement (or in conjunction with it): Helps in expanding the National Statement.
- Requirement for education recommended, i.e. Section in PhD for reflecting if ethical principles have been met.
- Ethics requires advocates or role models to influence practice; finding a champion to support and keep practice/process on track.
- Reviewers of grants who have understanding – i.e. to question, refuse, etc.
- Describes the need for equality between partners.
- Documents help to focus on community engagement.
- Highlight the point of a community decision to participate, versus an individual decision.
- Community awareness of the benefits of research.
- Make researchers and HRECs aware of issues to be considered.
- South Australian Health and Medical Research Institute (SAHMRI) 'Accord'.
- Aboriginal Health Council of SA (AHCSA) 'Next Steps'.
- Primary Care Draft Framework.

- Better training for Ethics Committees.
- Strengthen capacity.
- Change research culture.

Barriers

- Lack of awareness of documents is a significant issue; eg. people in primary care services do not know about the guidelines.
- No case studies of good practice.
- Should the two documents be integrated?
- Current model of doing research is very much research-driven as opposed to community-driven.
- Monitoring – how could HRECs monitor project as they progress, rather than just approving them at the outset?
  - Lots of scrutiny happens at the front end, but what happens after the community Letter of Support is endorsed, approved?
- HRECs capacity to insist on the process
- Documents need to clarify when *Values and Ethics* and *Keeping Research on Track* should be used, how it can be applied.
- *Values and Ethics* needs stronger input from Aboriginal and Torres Strait Islander researchers / epistemology.
- National Ethics Application Form (NEAF) – the tick box for Aboriginal participation is inadequate.
- *Values and Ethics* is punitive towards researchers – move away from punitive/risk language towards a more neutral terminology (page 5).
- Uneven implementation of *Values and Ethics* and *Keeping Research on Track*.
- No singular process – is a turn-off to researchers.
- Lack of resources for HRECs/lack of implementation/lack of strategy/lack of training
- Still feeling Aboriginal and Torres Strait Islander engagement is tokenistic.
- How to align views – worldviews: Aboriginal and Torres Strait Islander versus other.
- Funding – the money often comes in first before the community engagement.
- Focus on first steps of projects first – need funding to support this and time must be factored in.
- Research priorities should be <u>for the community</u>.
- Lacking systems/process to support local community priorities to come through and guide research.
- No monitoring system (good at application stage but not sustained throughout the entire process).
- Research which has been designed to exclude certain groups, eg. language groups.
- Having to go to two or more ethics committees for approval.

- There is a reliance on AHREC, so therefore other HRECs and researchers don't become as skilled in using these documents.
- Researchers are not familiar with these documents.
- The ethics process itself can be a barrier to the research.
- Researchers need to include Aboriginal people / communities at all stages.
- NHMRC should have a role in setting the playing field.
- Research 'Model' and 'Culture' not suitable for Aboriginal and Torres Strait Islander research.

Are there ethical considerations not covered in the current guidelines

- Usage of datasets without consent needs to be clearer:
    - Particularly those that can be used for secondary purposes.
    - Implications for whole communities and the perceptions that are then created.
- Who owns the intellectual property?
    - Who owns the database, who has the right to use it?
- How are the Aboriginal ethics processes covered in the National Statement - Guidelines for Ethical research in Aboriginal and Torres Strait Islander research should be part of the same document to then be considered as part of any ethics submission.

Best Practice

- Have stronger evidence of engagement with Aboriginal and Torres Strait Islander community and confirmation of support for the study – have an agreement in place before the study commences.
- Refer to 'ladder' of community participation.
- Recognition of cultural knowledge: (a) that is vital; (b) authorship; (c) remuneration of time.
- Engagement all the way through research process. "No token blacks". Note that one Aboriginal person may not have the necessary background/authority. It is important to engage with the most appropriate community person.
- Aboriginal Medical Services should define the terms of engagement eg. The Nunkuwarrin Yunti Memorandum of Agreement with the University of Adelaide.
- What empirical evidence is there to show how research is improved by the *National Statement, Values and Ethics, Keeping Research on Track*?
- National code for conducting Aboriginal research.
- Guidelines and training re how to use *Values and Ethics / Keeping Research on Track.*
- Refer to international best practice.
- Acknowledgement where good research occurs.

- Centralised online presence: need for a website on Aboriginal and Torres Strait Islander ethics.

Ethical considerations not covered

- Do not take into account the changed landscape of Aboriginal research, eg Aboriginal Medical Services are now involved in research.
- Cultural knowledge, input, expertise is not optional; it should be compulsory.
- Use of complaints as a means of monitoring is inadequate.
- Consider projects having 'provisional' ethics approval and monitor their progress.
- Too many documents – *National Statement* (Legislation) / *Values and Ethics / Keeping Research on Track* / AIATSIS ethics guidelines –(general Aboriginal concepts not specific to research).
- Are the six ethical principles in the National Statement?
- Documents don't cover monitoring of research, implementation and training.
- Feeding back to community high priority.

New and Emerging Issues

- Relationships with ethics committees – trust needs to be improved.
- Impact on communities i.e. taking body parts, body tissue.
- Changing socio-environmental factors means questioning if health outcomes or risks are same for Aboriginal/non-Aboriginal populations, i.e. perinatal research. Aboriginal mothers versus non-Aboriginal mothers in Aboriginal and maternal infant care AMIC programs, or Aboriginal children versus non-Aboriginal children.
- Stem cell and transplantation research; organ donation.
- Need broad AHRECs but also an increased need for specialised committees as well, (AHREC are not experts on all issues).

General

- Outcomes must benefit Aboriginal communities.
- The principle ''survival and protection"– is outdated. Consider other terms such as cultural integrity.
- What does capacity building mean? Guidelines need to describe what that capacity building is, what difference did that make?
- Case studies / exemplars would be useful throughout the document/s.
- Cultural shift required – ie. research/academic world needs to understand the community worldview.
- In South Australia, SAHMRI has developed an Accord; worth referring to.
- There needs to be better two-way relationships between researchers and communities.
- Need a better way for doing research, guidelines are only part of it.
- Guidelines are silent on funding.

- Much tension around funder's pressures versus community pressures and needs. Why not build in a winder at start of process, to allow more time to work things out at start of process.
- Ethics Committees are under-resourced. There are huge demands on ethics committees, who work without remuneration.
- Align our points of view – from start to end of research process: i.e. different meanings of values, words. Aboriginal values may be different for different audiences. Be wary of importing ideas, theories from completely different groups, contexts, etc.
- Any researcher proposing new research not only needs to show engagement with communities but also to be required to consider if the findings can be transferable across populations/communities.
- Supply resources – not specifically money but for example transport from remote communities. Communities should not be out of pocket due to participation in research.

'Researching Right Way' Brisbane consultation notes:

Stakeholder Experiences of using the NHMRC guidelines *Values and Ethics* and *Keeping Research on Track.*

Community experiences of research and ethics processes

The Brisbane consult talked about *Keeping Research on Track* (KROT) being used as a handout as the first step in the research engagement process. Participants also talked broadly about the application of the National Ethics Application Form (NEAF) and how this was not used consistently across institutional ethics committees.

The *Values and Ethics* document was often provided to new students coming into the Aboriginal health space. Community members expressed a concern and wish that ethics committees be assessed as competent before assessing ethics applications and that standardized training is available so that there was consistency across committees.

KROT was used in the community and by researchers, but both agreed that this document could also be shorter.

Researcher experiences of the research and ethics processes

Researchers and community expressed concern that the *Values and Ethics* document was overly busy and could be simplified. There was also concern that the fact there were three main documents was a concern and questions were raised about which took precedence in the assessment process. Was it the National statement or does *Values and Ethics* override this?

Some researchers used KROT as a way to engage community in initiating the research process and found it useful for this. It was also used to build community capacity in the understanding of the research process.

Some researchers talked about the James Cook University (JCU) Indigenous health research workshops and said this workshop should be available nationally.

Some researchers said they avoid research in these areas because it was 'hard work' doing the six criteria.

Researchers also wanted better explanation of where the point came in relation to ticking the box as to: *involvement of Aboriginal people as research participants*. 'How many people do you need before you need to tick the box?'.

Ethics committee experiences

Some HREC members did not receive the *Values and Ethics* document or the KROT when they joined the committee. They also expressed a strong desire to have training in assessing ethics application using the *Values and Ethics* document.

Some university ethics committees had established different procedures when it came to assessing ethics application where Aboriginal people were a focus. Griffith University had two rotating positions on its committee. Others had an Indigenous sub-committee.

Suggestions for improvements to documents:
Values and Ethics

- Provide resources for ethics committees (training and case studies)
  - Have examples available for ethics committees on what was done poorly in the past, so they understand the need for *Values and Ethics* and KROT and also have resources demonstrating good practice.
  - Training and professional development for:
    - Researchers
    - Ethics committees
    - Community
  - A clearer definition of 'health research' is required perhaps in the national statement, but also in each of the docs being evaluated
  - Merge all three documents and make the Values in the *Values and Ethics* doc universal in health research, this would stop researchers skipping over them.
  - There has to be a way to invest so that researchers have a sense of responsibility to 'tick the box' and also create a sense of accountability.

Keeping Research on Track

- Shorten it a bit, and use as the basis of an electronic resource
- Greater emphasis is needed on translating research back to communities

- Greater need for capacity building and feedback

Other suggestions for improvements:

Participants expressed a need for:

- A resource where people can go (Researchers, HREC, community) to seek advice, nationally to jurisdiction to region to the local level
- Improve capacity building in communities so they know their rights in the research journey
- HRECS bring in expertise when they need it
- Establish an Indigenous health research ethics council in Queensland, as this doesn't exist
- Establish a more synergies system for ethics (HOMER)
- There must be a better way to connect Govt agencies, consultants and universities as they also produce new knowledge's (through evaluations and the like) but they are exempt from the ethics process.
- The annual reports to committees must demonstrate continuing support for the research from the community.
- Commit funding to print resources and to get them out to the placers where they are needed and alternative methods are needed. E.g. DVD and other mediums.

Emerging issues
- Monitoring and accountability needing to bolstered
- Genetic research/biomedical samples
- Data Sovereignty, custodianship and ownership
- Forensic archaeology

'Researching Right Way' Broome consultation notes:

Stakeholder Experiences of using the NHMRC guidelines *Values and Ethics* and *Keeping Research on Track.*

Experiences of using the Guidelines

- Generally, people reported that there is an issue around the power dynamic / power imbalance associated with Aboriginal health research.
- When issues arise in relation to research, universities can tend to close ranks to protect each other; communities get fobbed off not to deal with the academics and issues:
  - Arrogance is an issue (i.e. on the part of universities/research institutions).
  - Research directed from Melbourne and Perth – especially don't understand local issues and don't see why they need to get ethics.
  - Appropriation / honesty in research is an ongoing issue.

- Power in the research community– hierarchical way of seeing human beings; universities hold the funding and therefore the power, but this needs to be changed for a more respectful relationship.
- Researchers often don't build in consultation, dissemination, capacity building into projects.
- Community consultation is often 'tokenistic'.
- Researchers need to take the time to develop real, genuine relationships; credibility takes a long time to build up.
- Partnerships must be genuine.
- External researchers are often surprised what they need to do; often surprised about the challenges when it comes to actually doing the work. Potentially these matters could have been covered in the ethics application process.
- Need more partnering with other researchers to do research in an ethical way.
- Tension about career researches versus getting change on the ground.
- The right way is to work with the community to address a community identified issue.

The Documents

- Other disciplines use the documents. *Values & Ethics* document is good for this.
- AIATSIS document also comes into play, has some content worth considering in the NHMRC documents.
- *Values and Ethics* doesn't help do an ethics application; the language is a problem. It is dense, hard to read; it needs simplifying; "*Made me feel like I was jumping through hoops rather than being true*"; need to address every point and then it is like ticking the box.
- Some people had not seen the documents before.
- Documents should be promoted to undergraduates, post-grad, researchers.
- Promote documents by having workshops at local level.
- Should be easier to read; include steps; include checklists.
- See the Canadian guidelines.
- Too much writing! There needs to be a clearer format to make it easier to read.
- There needs to be links to appropriate ethics resources.
- Practice examples such as video clips; copies of templates.
- More use of interactive forums; Social media (eg. Facebook, Twitter).
- There should be a website with Frequently Asked Questions (FAQ's); a logged help site.
- Flow chart – include who to speak to so as to help demystify the process, by state.
- Include a glossary and checklist.
- Include rationale about the need for ethics processes.

- Knowledge / IP should remain with community.
- Create university-specific guidelines.
- Have Aboriginal Ethics Committee guidelines.
- Consider having a compulsory aspect re understanding and engaging in Aboriginal research (eg like vivisection licence).

- ***Keeping Research on Track*** – is more useable; easier to read; set in points, is simpler; has practical things to do.
- Both documents would benefit from use of examples/exemplars/case studies.
- Need research training.
- Training local researchers.
- Need to unpack partnership –what is genuine partnership? What does it look like? How can it work on the ground?
- There needs to be more responsibility / accountability to Aboriginal community.
- Dilemma re participatory action research versus bio-medical focus.
- Focus on community-based research, eg birthing.
- Needs a prevention focus.
- Link the guidelines to NHMRC funding values process.

General

- Cultural shift required in understanding what Aboriginal health is; what Aboriginal health needs are; how to undertake research respectfully.
- Local priorities / locally driven research.
- Funding – funding should related to local need.
- Caution re: curiosity research; researcher-driven research.

'Researching Right Way' Cairns consultation notes:

Experiences of ethics process by the community

The Cairns consultation described the situation of many health researchers coming into Aboriginal and Torres Strait Islander communities, but that the opinion of communities and individuals was not being respected. Many assumptions about Aboriginal and Torres Strait Islander communities and individuals are still being made in the health research space.

Participants described growing tensions between health service providers and researchers and the competition for resources. Services believed researchers are taking resources away from services and are not giving back. There were some discussions in the workshop about services that are regularly involved in research and how this was occurring because there is capacity to do so. There was some suggestion that a focus could be on areas where no resources exist. There was also discussion about who researchers approach in communities. Some participants described researchers approaching people who may not have the capacity to make informed decisions about the research being proposed, or because it was 'easier' via this person.

The importance of providing feedback to the community of research outcomes was discussed at length. Participants believed there had been limited feedback of the research outcomes being returned to community. Community participants emphasized the need for translation of research back to the community to deal with the issues identified in the research.

As per the Thursday Island consultation feedback, the Cairns consultation identified that there are no community based health research approval processes in Queensland. Initially the research must go to the ethics committee at Brisbane (QLD Health) and if the research is to be undertaken in the Cairns region, the research protocol is referred to the Cairns based ethics committee. There is an Aboriginal/Torres Strait Islander person on this committee. Once approved through this committee, the protocol must receive site specific approval (SSA) at the local health service where the research is proposed.

While there is no community based ethics process in Queensland, Wuchopperen Health Services described a process they are about to commence to determine community based health research priorities locally.

For both ARC and NHMRC funding, participants suggested longer lead times for the research proposal development and funding of consultation processes to be incorporated into the research process.

Community participants and organisations also suggested a greater emphasis in research proposals for investing more into community based researchers and into capacity building as part of the research process.

In terms of the *Values and Ethics* document participants suggested reworking the document as it was not well understood. They suggested different presentation methods as well. They also suggested more contexts needs to be added to *Values and Ethics* so that researchers understand more about the history of health research. This needs to be at the front of the document.

Keeping Research on Track was described as a good document, but it could be shortened and there is a need to have it available in different modes such as video and brochure. They both need to be disseminated much more widely.

Monitoring of the research process was identified as an area that required bolstering. Annual progress reports that are required by ethics committees should also include indicators for reporting by the researchers back to communities.

Researcher experiences of the research process

Researchers sometimes see the *Values and Ethics* document as adding to the already onerous ethics process; they didn't see addressing the Values as assisting with the research process. Often researchers were looking at how to do the research without addressing the

six values because they had no training or awareness on what to consider in addressing the values and they believed that addressing them added to the ethics workload.

Some researchers mentioned an ethics training program run through James Cook University that is based on the *Values and Ethics* document which might be helpful to researchers coming into the Aboriginal and Torres Strait Islander health research space: see http://www-public.jcu.edu.au/researchservices/ethics/atsi/JCUPRD_054033. There is an introduction to Indigenous research taught by an Aboriginal Professor.

Both community and research participants wanted to see more robust methods for the way research was conducted. Suggestions included the development of templates for research agreements as a suite of template documents.

A researcher present at the workshop stated that the ethics process was quite detailed, complex and could become quite long depending on the number of sites proposed for the research.

Ethics committee experiences

Both documents were not routinely available to new ethics committee members when they joined the committee. Usually assessment of Aboriginal and Torres Strait islander health ethics proposals were forwarded to the ethics committee member with Aboriginal and Torres Strait Islander health research experience and assessment of the proposal was left to this individual.

There is no standard training available from the NHMRC on how ethics committees should assess the six values in *Values and Ethics*.

Committees didn't know where to look to find expertise with Aboriginal and Torres Strait Islander health research.

Suggestions for improvements

Participants expressed a need for:
- need a phone application or central website where all relevant information is available
- DVD and short pamphlets
- Social media promotion
- Guidelines need to include short contextual explanation of Aboriginal and Torres Strait Islander history of health research / cultural and historical bad experiences ie. why they are needed.
- Better presentation: make it clearer.
- There seems to be lots of low quality Aboriginal and Torres Strait Islander health research being done and we need to look at the impact this has.
- Design a risk assessment tool for researchers to present to the community regarding risk as well as benefits.

- Use more examples of good and bad practice in the guidelines and more digital examples ie. Researchers taking digital camera photos of people in the research without real consent. Genetic examples.
- Develop examples of community feedback summaries in plain language.
- Develop examples of relevance to biomedical lab research.
- Describe and promote the principal of active listening in research as a value - (by researchers to community).
- Much greater promotion of the *Values and Ethics* document and *Keeping Research on Track*.

Process issues and suggestions

Ethics committees and consideration of establishing Aboriginal and Torres Strait Islander Health research subcommittees in each jurisdiction.
- Have a mechanism to determine community research fatigue.
- Ensure feedback is done and is appropriate (with examples).
- Gaps in research need to be addressed rather than just logistically easy projects.
- Timeframes for research need to include upfront consultation/negotiation and planning, it is currently too short for adequate consultation.
- Embedding *Values and Ethics* in a formal structure for research governance.
- Bigger research investment in community priorities.
- In NHMRC research funding, add more weight to community researchers versus track record.

Emerging issues
- Research fatigue
- Genetic research/biomedical samples
- Research governance structures
- Data linkage and databanks
- Cultural knowledge in research and ownership of cultural knowledge in the research process
- Social media and research

'Researching Right Way' Canberra workshop notes

Stakeholder experiences of using the guidelines *Keeping Research on Track* and *Values and Ethics.*

a.   **Community experiences of research and ethics processes**

- Community participants expressed a need for researchers to learn how to engage in the Aboriginal health research space better. They also needed to know about the political and health research landscape through special measures such as 'Close the

Gap' and understand health research through the prism of the *United Nations Declaration on the Rights of Indigenous peoples*.

- Some community participants were concerned about the level of competence of researchers conducting research in communities. They were also concerned about the level of evaluation going on in communities and suggested that evaluations should also be scrutinized through and ethics process.

- *Values and Ethics* document was considered relevant but there needed to be better explanation for research being proposed to both community and to ethics committees.

- Community participants said that researchers needed to be made to address the values not just include 'motherhood' statements.

- Participants also wanted clarity around consent processes and how consent in the research process is defined and agreed to.

b. Researcher experiences of the research and ethics processes

- Researchers stated they were aware that the research community was using Keeping Research on Track to guide development of the ethics proposals because it is more intuitive and uses less complex language.

- Some researchers said there was a need for a national approach to ethics approval in Aboriginal health research (similar to the NHMRC's National Approach to Single Ethical Review of Multi-Centre Research), as there were too many ethics processes required across jurisdictions.

c. Ethics committee experiences
- Some committees were unsure that they were assessing Aboriginal health research proposals adequately and expressed a need to have resources for ethics committees (training and case studies).

- Committee members also suggested that there be better linkages better the *National Statement, Values and Ethics* and *Keeping Research on Track* documents.

- For committee members who were tasked with assessing Aboriginal health research proposal, some talked about the power imbalance on committees, particularly between lay members and clinicians.

- Some committees didn't have Aboriginal health expertise represented and participants stated that institutional culture has a lot to do with how Aboriginal people are incorporated into HREC structures.

- There was discussion among ethics committee members about the acceptance (and recognition) of ethics applications from other institutions such as AIATSIS. Therefore if an application had been approved by AIATSIS, other committees automatically approve the research proposal.

d. Suggestions for improvements to documents

V. *Values and Ethics*

- Too theoretical need more examples and case studies.
- Values are ok, but need to be unpacked.
- Incorporate the definition of Aboriginal health and wellbeing into the front end of the document.
- Explain better the notion of spirit and integrity.
- Incorporate key questions with each of the values, so researchers understand the values better.
- Provide case studies and examples of research where the values have been addressed well.
- Need more resources to promote the 'right way' of doing research.
- Some of the context at the front of the document can be removed into an appendix.

VI. *Keeping Research on Track*

- Shorten it a bit, and use as the basis of an electronic resource.
- Greater emphasis is needed on translating research back to communities.
- Greater need for capacity building and feedback.

e. Other Suggestions for improvements

Participants expressed a need to:
- Incorporate evaluation into the ethics assessment.
- Consider stolen generations research and dealing with issues including identity and publishing stolen generation stories.
- Consider documents in Aboriginal languages or in other formats for community.
- Training for committees and professional development around the application of the Values.
- Do the values in the Values and Ethics document need to be incorporated into the National Statement, should all research be conducted this way?
- Develop a framework for further revision to the documents, so it is not too long before a further revision/evaluation is conducted.
- Roll out a program of:
  - Capacity building of ethics committees to increase assessment of values within committees;
  - Capacity building of researchers to increase ability to address values;
  - Empowering communities to plan their involvement in research, not just waiting until researchers are out in communities.
- Develop a national register of Aboriginal and Torres Strait Islander research.

'Researching Right Way' Darwin consultation notes

Stakeholder Experiences of using the NHMRC guidelines *Values and Ethics* and *Keeping Research on Track.*

Community experiences of research and ethics processes

The Darwin consult group talked about the *Values and Ethics document* being hard to understand, especially when applying the values to research such as data linkage research.

Community consultation as part of preparing a research proposal is not funded and this devalues the community role in the research process. The powerbase in research resides with researchers as this is where the funding resides.

It is hard to know who researchers should go to in communities and it can often be burdensome on communities given the amount of consultation occurring in the health and other research space.

Peak bodies such as the *Aboriginal Medical Services Alliance Northern Territory* (AMSANT) are overwhelmed with the sheer volume of proposals coming through, which causes capacity issues given limited resources. AMSANT has developed a policy on the research process which is used as a guide for organisations seeking their advice in the health research space:
http://www.amsant.org.au/attachments/article/88/AMSANT%20Research%20Policy.pdf

Community organisations want more training for HRECS to assess research aimed at Aboriginal people around proper processes. With the *Values and Ethics* document it is important to remember that it was meant to be contextualized to the local context. The group also wanted more Aboriginal and Torres Strait Islander commissioned research, driven from the community as the 'research broker' turning the process around.

Participants also wanted greater diversity on HRECS, as there was a feeling that they were dominated by clinicians. Also described was the importance of having more Aboriginal people listed as chief investigators on research projects, as well as space for community members in the research team and in the publishing phase of research.

Community participants believed that HRECs should be funded to have training in assessing research involving Aboriginal people and that HRECs need to be exposed to communities.

Despite the difficulties described participants did not want researchers and HREC's to see Aboriginal health research as 'too hard', rather that there are processes that can be followed that will improve the research quality and output.

Researcher experiences of the research and ethics processes

The researchers present at the workshop stated that the ethics process was quite detailed, complex and could become quite long depending on the number of sites proposed for the research. Also they weren't sure where they could go and who the right person/people to go to were.

All research with Aboriginal people should have chief investigators or associate investigators that are experienced in the Aboriginal health research space to advise others without experience.

A national level research brokerage system could be established which researchers and community could contact for partnering in research or to generate research priorities.

Researchers want and need time to build relationships with communities.

Ethics committee experiences

Both documents were not routinely available to new ethics committee members when they joined the committee. Usually assessment of Aboriginal and Torres Strait islander health ethics proposals were forwarded to the ethics committee member with Aboriginal and Torres Strait Islander health research experience and the assessment of the proposal was left to this individual.

There is no standard training available from the NHMRC on how ethics committees should assess the six values in *Values and Ethics*.

Committees didn't know where to look to find expertise with Aboriginal and Torres Strait Islander health research.

Allow a process in all HREC's where researchers can address the ethics committees to resolve questions about the proposal and to expedite the process.

Suggestions for improvements to documents:
Values and Ethics

- Develop a checklist that can be used as a tick and flick
- Build a database of examples specific to each value, so researchers can see what these mean and how they apply in the real world (including institution based examples).
- Training and professional development for:
    - Researchers
    - Ethics committees
    - Community

Keeping Research on Track

- Develop a checklist that can be used as a tick and flick

- Attach a description of the metaphors about the research process such as the East Arnhem Land story
- Put in some bottom up stories, rather than top down (the current way it is written).

Other suggestions for improvements

Participants expressed a need for:
- A hotline where people can go (Researchers, HREC, community) to seek advice
- Fund HRECS to engage with local Aboriginal communities
- Link jurisdictional documents to *Values and Ethics* and *Keeping Research on Track* (eg. AMSANT Policy and others)
- Develop a checklist that can be used as a tick and flick.
- Allow a process in all HREC's where researchers can address the ethics committees to resolve questions about the proposal and to expedite the process.
- Build better self-populating forms e.g. National Ethics Application Form (NEAF) and other ethics application forms.
- Where appropriate, have Aboriginal people as chief investigators in research.
- An example is needed for large national studies such as the National Health Survey on how the Values can still be met.
- A 'clearing house' for ethics resources.
- Establish a process of random auditing of ethics applications for recognised ethics committees.
- Ensure there are units with university degrees on ethical processes in research to ensure that *'ethics is not a footnote, it is the process'*.
- Difference blindness is not well understood and needs to spelt out.

Emerging issues

- Research fatigue.
- Genetic research/biomedical samples.
- Data Sovereignty, custodianship and ownership.
- The concept of continuing consent throughout research, not just at the beginning.

'Researching Right Way' Hobart consultation notes

Stakeholder Experiences of using the NHMRC guidelines *Values and Ethics* and *Keeping Research on Track.*

General feedback

- The guidelines are 'hit and miss'- some students know of, and use the guidelines; other people undertake research but never consult them.
- HREC's need orientation around the documents.

- There is no Aboriginal and Torres Strait Islander Ethics Committee in Tasmania.
- Need a formalised process for ethics approval.
- There have been issues around letters of support. Being asked to write letters of support can put organisations or committees in the precarious position of being asked to support research work, without there being a working relationship already established; without knowing all that is required to commit support to the project.
- It was reported that guidelines are sometimes seen as an 'imposition' to getting work done; an infringement of academic rights.
- Technological advancements need to be covered in the guidelines.
- There are potential issues that need to be considered in the guidelines, where human material is stored in 'bio-banks'. This is a matter even mainstream ethics committees can struggle with. People are divided as to the pros and cons; nonetheless it is a matter for consideration in Aboriginal and Torres Strait Islander ethics.
- Identification issues in data (eg. a rare disease, individuals can potentially be identified).
- Need to determine/define – what is 'research of benefit' (ie. whose benefit?)
- There is too much descriptive research – ie. how bad things are.
- Indian (ie. continental India) Indigenous people have been doing Indigenous knowledge patents (IPs) very well.

Best practice

- Lots of resources (time) needed to do best practice well; then it becomes an issue between doing research versus service delivery.
- Cooperative Research Centre for Aboriginal Health – was (is) about community-instigated research.
- Note that government work is not subject to ethics processes.
- Community should be aware of ethics in research.
- Need to reference Human Rights documents – research and ethics around research should sit within a rights framework.
- Document should be revised to include health and wellbeing; place within the context of the Aboriginal definition of health.
- Suggestion that guidelines be one document only.
- Provide a checklist for working through the ethics processes.
- Make the document language more contemporary.
- Ethics Committee people are time-poor, but asked to undertake heavy workloads, for no payment.

'Researching Right Way' Melbourne consultation notes

Stakeholder Experiences of using the NHMRC guidelines *Values and Ethics* and *Keeping Research on Track.*

Experience of the Documents

- *Values and Ethics* – Document needs to be more usable, easier to understand. Both documents require a summary of key points.
- People didn't really know about *Keeping Research on Track* [ie. non-Indigenous people working in the research sector].
- Research might not get done because Aboriginal research can be perceived as 'too hard', but guidelines could assist.
- Knowing how 'new' organisations can engage with Aboriginal and Torres Strait Islander people for example the key messages for new researchers (new to Aboriginal health).
- Value - Reciprocity – how does it work; what does it mean for a project; how can it be enacted?
- Values are well expressed and still relevant, but a summary statement would be helpful.
- Value - Survival and Protection – perhaps frame more positively.
- Values are open to interpretation.
  - Case examples of how values work and apply would be useful.
- Culturally appropriate methodology (decolonization, qualitative descriptive – illustrate through case studies).
- Best research is where community has identified the research.
- *Values and Ethics* document is useful for health research.
- Mixed responses on use of guidelines. Some useful; some did not use – some did not know about them.
- Communities are generally using the National Statement. The *Values and Ethics* statement is not up to date – it references the previous national statement.

Barriers and Enablers

- Uses other ethics guidelines with research fields and organisations.
- Similarities with AIATSIS guidelines.
- It is time consuming sticking to guidelines rather than being out on the job building relationships with community.
- Keeping communities aware of changes to guidelines.
- Have Aboriginal researchers. Community would have a more engaged approach working with Aboriginal researchers.
- Aboriginal unit should review research and advises research time.
- Privacy and confidentiality has improved over the years.

- Communities are now asking 'What's in it for us?'
- Aboriginal communities may be excluded from disease specific research if values/guidelines are too hard.
- Community needs to be aware of the purpose of guidelines and research.
- Thoughts from community and their thoughts of the research being conducted.
- *Keeping Research on Track:* Is 'Establishing Relationships' the best way to start? For example, community needs to know what the research is about and what it involves before deciding to make the effort to establish a relationship.
- Practical questions for researchers to guide them in the practice of applying the principles.
- Practical advice on forming / engaging with an Advisory Panel/Committee. Participants also contribute to providing advice and guidance for the project.

General Comments

- Guidelines – Clarify what reciprocity means – who expects to get what? Sometimes its reimbursements for time, eg vouchers; lunch.
- Ethics approval application –clarify how many Aboriginal and Torres Strait Islander participants a research project needs to require applicants to explicitly address guidelines and how they will be implemented in the project.
- Guidelines need to be updated with respect to reference to *National Statement.*
- Standardisation of reporting to Ethics Committees required.
- Resources - for capacity building; for the time required to implement the guidelines; for feedback of results to community and individuals; for a Victorian Aboriginal Ethics Committee, notwithstanding issues of representation and bureaucracy.
- Provide audio-visual resources in language to allow communities / [or committees?] to apply the guidelines.
- Other groups doing research such as consultants, ABS, marketing companies, internet surveys – are not required to follow guidelines?
- National Guidelines – Chapter 4.7 – are very brief, and weak on guiding HREC membership input by Aboriginal and Torres Strait Islander representatives. Does not specify how the six values (Aboriginal specific) align with the four general guidelines.
- Best practice eg – Victorian Department of Justice via Koori Justice Unit.
- Applying guidelines and addressing them in ethics applications.
- Publishing versus community engagement and priorities.
- Adherence to new guidelines for existing / ongoing projects.
- Moving from compliance to trust.
- Getting better at recording the process of gaining trust in the lead up to compliance
- Aboriginal communities are becoming more savvy about what they can expect from research – 'if it's written down it must be true', which is not necessarily. Need community input at reporting stage ('peer review') to prevent damaging and untrue interpretations and broadcasting of misinformation.

- Consultation with a wide range of community representatives.
- Control by and benefit for community.
- Refer to other guidelines such as Lowitja publications; VACCHO website.
- Risk of tick-box approach to consultation with Aboriginal communities – but this also applies to everyone.
- The guidelines need to be relatively flexible – example of delay in research because of trying to meet requirement of the guidelines.
- Have things improved in last 10 years?
- Challenges – local politics; research pressures to produce/publish; online, social media revolution

New and Emerging Issues

• Importance of emerging Aboriginal and Torres Strait Islander academics/researchers. What are the issues confronting them; are they networking; how can we hear from them?

• Case – Walter & Elisa Halal Institute – biomedical research; pilot research; casting a wide net; collaboration with experienced NT researcher.

• Victorian Aboriginal Community Controlled Health Organisation (VACCHO) Aboriginal community controlled organisations; the umbrella body. Importance of member meetings; need a formalised process for engagement and cooperation with VACCHO (but not individual members). Identified research priorities; RO status evolving potential.

• Comment on the lack of Aboriginal Ethics Committees. There are different ways on engaging Aboriginal and Torres Strait Islander people, or representation on committees - usually through advisory groups.

• General comment – VACCHO gets a lot of requests for research, because there is a lack of data on Aboriginal health.

• Lots of activities in addition to the guidelines for researchers to get across issues related to ethics and doing research involving Aboriginal and Torres Strait Islander peoples.

- Consider that not all communities are the same. The principles of research should always be the same.

• The different guidelines specify different principles and would be good to ensure that these are aligned across the guidelines.

• Agree there should be a national values statement but the six values in the *Values and Ethics* document are still very relevant and important. It is important to remember history.

• NHMRC guidelines are specific to health research. However, we need to consider the meaning of health [definition of Aboriginal health].

•   Different research committees – eg clinical trials versus social health research committee – use different guidelines / emphasis different elements.

•   In New Zealand, researchers have to justify why if Maori people are not included in their research.

•   Committees are relying on expertise of researchers and sometimes researchers turn to committees for answers.

•   Important issues about control of information.

•   Reciprocity and respect keeping communication going – best to do this 'the long way'.

•   Capacity-building parts are important – there is a real bottleneck of people who can communicate the research.

•   How can the revised guidelines be written in such a way that it captures these tensions?

Revision ideas

- Value for summary/ intro for both documents
- *Keeping Research on Track* – is a much better format, easier to use than *Values and Ethics*. *Keeping Research on Track is* easily identified for what it is, its purpose is clear.
- Case studies - include case studies to illustrate values, to make them more meaningful.
- Step by Step guide for researchers.
- Checklist for both applicants and for committee.
- Need more awareness that there are two separate documents. They both need to be clearly cross-referenced.
- Working agreements to formalise partnerships and relationships.
- Guidelines need to be more explicit about a principle to formalise relationships to ensure genuine and equal partnership. This also protects from changeover in personnel.
- Acknowledge diversity of Aboriginal and Torres Strait Islander communities.
- Include / make reference to UN Declaration on the Rights of Indigenous peoples.
- Need to consider how to cover non-traditional methodologies, eg use of cameras (spirit).
- Guidelines around social media.
- Standardisation / harmonisation of application processes and report-back process.
- Organisations/institutions should understand, acknowledge and promote the importance of ethical research.

-

Best Practice Discussion

- Steering Committee of Aboriginal and Torres Strait Islander people.
- Identifying key gatekeepers.
- Monash / Swinburne – NHMRC guidelines followed carefully.
- Mercy Hospital for Women – referred by Aboriginal Unit before coming to HREC.
- Issues – compensation.
- Importance of ATSI participation at every level.
- Serious institutional support and commitment.
- Long term sustainability factored in.
- Is the research producing change?

New and Emerging

- NCIS not covered in current guidelines.
- Ownership of data – communities own data as well as university/researcher.
- Offer research data back to participants – share with individuals; pass onto children and future generations.
- Consent forms – explain data / tissue used for this research and other stuff in the future = how this is worded on the form and explained?
- Genetic data – storage of tissue sample – informed consent. How to cover connection to spirit/stories/customs – explain it's different for different communities.
- Diversity of communities – research to reflect the different lives of Aboriginal and Torres Strait Islander peoples – not just one group.
- Link to National Statement on Research Ethics.

'Researching Right Way' Perth consultation workshop notes

Stakeholder Experiences of using the NHMRC guidelines *Values and Ethics* and *Keeping Research on Track.*

General comments

- '*If you don't know about the guidelines how can you use them*'?

- Process is back to front – research ideas should come from the community.

- Currently, the reference point for research is the researcher not the community – all the rewards are for the researcher – where is the community benefit?

- Research findings too often are presented from the researcher's point of view, not the community point of view.

- There needs to be a better framework that sits around the research process that reinforces the rigid process of doing research with Aboriginal peoples – and gives the values more relevance and meaning. Guidelines are only part of the ethics process.

- NHMRC guidelines are silent on specific funding or the requirement to fund the involvement of Aboriginal people and organisations – it costs money and time for organisations to set up focus groups/connect to community participants – consequently the guidelines set up the organisation to bear the costs of implementing the guidelines.

- There is often tension around funding pressures versus community needs – build community consultation time into project and fund this.

Barriers

- Ambiguity about when to apply the guidelines.

- Little or no awareness of the guidelines; availability / awareness of ethics (raised in several working groups).

- Ethics often perceived as 'too hard'; prevents thorough research, eg. Aboriginal population excluded.

- Limited skills, limited expertise on ethics committees – need confidence, capacity to process documents; there should be access to regional people to sit on ethics committees for particular needs, particular projects, ie. where certain expertise is required.

- Remuneration – value for ethics committee members; the workload of ethics committees is demanding and members should be remunerated for their work.

- Timing : Timelines don't always align with submission; timeline for application; timeline re funding and ethics process – delay to get approval.
- Guidelines can become a checklist rather than a mental and cultural mindshift. Risk of tokenism.
- Institutional change / cultural change needed– eg, Aboriginal representative seen as working for us rather than with us.

- NHMRC should offer training for community and ethics members about how to apply guidelines.
- Letters of Support – communities are inundated for letters of support. It is not their core business and they are not funded to provide letters of support.
- Perception that additional effort and sensitivity is required in Aboriginal research.

Enablers

- Plain language is an enabler – especially *Keeping Research on Track.*
- Institutes can demonstrate leadership by using guidelines and have strong use of guidelines.
- Consistent guidelines at a national level.
- Guidelines can crease discussion and awareness.
- Gaining an Aboriginal representative.
- Requirement to use guidelines to carry out research.
- Building proper relationships and maintaining connections.
- Proper consultation with the community enables better process.

Gaps in current guidelines

- How to address research not principally targeted at Aboriginal community, but a significant proportion of Aboriginal people, eg 25% involved?
- Principles in Guidelines – many would be good to apply across the board to all research eg collaboration, eg community riven research.
- Lack of homogeneity in Aboriginal groups – lack of understanding and applying the *Keeping Research on Track* guidelines.
- How do the guidelines accommodate new researchers, eg students – how does it look in practice?
- How community members or participants interpret the guidelines. Need to empower participants.
- Funding bodies recognising the process of ethics.
- Research topics from community:
  - Breadth of ethical considerations across research modalities; case histories of how good Aboriginal and Torres Strait Islander research has been done.
  - More user-friendly, easy to read guidelines with practical case examples.
  - Consider AIATSIS guidelines.

Emerging Areas

- Internet/online/social media – ethics for Aboriginal and Torres Strait Islander people. Use of these technologies eg for follow up of research participants in a culturally appropriate way.
- Aboriginal identity in all databases is defined differently – is there an ethical issue here? Eg for genetic research?

- Is it important to have a discussion to pre-empt any issues, not just 'rural versus urban Aboriginal peoples' ie. Preamble about the heterogeneity of Aboriginal and Torres Strait Islander peoples.
- Genetics and stem cell research.
- Data linkage ; comparative studies.
- Research conducted by Government departments, eg especially education department, health departments, eg. psyche testing.

The documents

- Principals need further articulation, look like 'motherhood' statements.
  - Eg equality – what does that mean? Requires more context.
- Language, especially 'Survival and protection'- could be framed better, eg. revitalisation, resilience
- Do we need an additional value re. connectness?

Inconsistencies

- Need direction around researching genetic material – future use and community permission.
- Guidelines of using, eg. historic material - especially when samples not taken ethically.
- Archival material (eg Battye library) – what obligation do researchers have to contact owners of material to use it?
- Legal and or community and/or family and/or individual?
- Implicit paternalism in documents that communities have limited power/agency.
- Current or historical ethical principles.
- International researchers – working with Aboriginal communities – how are they made aware of protocols, ethics.
- What and who is the community? - who is the appropriate community person to contact? Researcher can contact anyone then 'tick the box'.
- Ethics around producing and using digital material, eg social media.
- Ethics approval given before community consultation, but researchers need to engage community prior.
- A positive aspect of *Keeping Research on Track* that it is a model of participation and can be used for service development for Aboriginal health care services.
- Limitations in current guidelines – needs to apply to all types of research and info/data collections, eg surveillance data, data linkage, genetics, bio-bank research, etc.
- Need clear direction about how to consult with the appropriate person in community. There is no one linear approach researchers can take.
- Aboriginal people need to understanding that they have authority over research done on their lives.

General

- Need more emphasis regarding the needs for research. It must be community driven.
- Need to educate researchers around the primary objective of community benefit.
- Need more information / guidance around ethics processes.

'Researching Right Way' Sydney consultation notes:

Stakeholder Experiences of using the NHMRC guidelines *Values and Ethics* and *Keeping Research on Track.*

f.   Community experiences of research and ethics processes

- Community participants expressed a need for researchers to learn how to engage in the Aboriginal health research space better.

- Values and Ethics document is too vague and open to misinterpretation. Ethics is often an afterthought and the methods are already developed, so there is limited scope to change this. Researchers are approaching community with methods in place and are usually not willing to change this.

- What checks and accountability apply, how is this done and which guides do you use: NHRMC, GERAIS (AIATSIS guidelines), AHMRC?

- Community participants felt that researchers needed to be more transparent and honest with community and this would build trust. More is needed in the research process about translating research outcomes back into communities to make changes.

- There needs to be better ways for communities to have a greater role in monitoring of research and the research process from the community perspective. This does not currently occur.

- Who owns the data collected from research – this needs to be explicit in the development of research processes.

- Researcher experiences of the research and ethics processes.

- Some researchers believed GERAIS (AIATSIS ethics guidelines) and AHMRC are more specific and easier to understand and apply.

- Participant payment is not addressed.

- Intellectual property is not addressed.

- Researchers expressed a need to better understand where to go in seeking to build community relationships.

- The *Values and Ethics* document is too vague.

- Researchers expressed concern about the length of time and the additional work the ethics process adds.

- Adding care in the research process so that the researcher is not reinforcing a negative stereotype.

- Being aware that long term funding of research does not mean longevity of relationships – this needs to be monitored.

- 'Researchers become overwhelmed by what needs to be done, so they do nothing'.

- Researchers find it hard to know where to go and how to establish relationships with the community.

- Researchers believed the *Values and Ethics* document was comprehensive, but that no models or examples of how to address the values were included as a guide. They also wanted additional guidance on processes locally to involve the community in research.

- Where this can be achieved, Aboriginal people should be chief investigators and named authors in the research process, community people should also be named authors.

- Ethics committee experiences.

- Some committees were unsure that they were assessing Aboriginal health research proposals adequately and expressed a need to have resources for ethics committees (training and case studies).

- Committees also wanted to understand more about what had happened in the past, so they could better contextualize why the values were required.

- Committee members also suggested that there be better linkages better the *National Statement, Values and Ethics* and *Keeping Research on Track* documents.

Suggestions for improvements to documents

- Provide resources for ethics committees (training and case studies).
- Have examples available for ethics committees on what was done poorly in the past, so they understand the need for *Values and Ethics* and *Keeping Research on Track* and also have resources demonstrating good practice.
- Training and professional development for researchers, Ethics committees, community.
- A clearer definition of 'health research' is required perhaps in the national statement, but also in each of the docs being evaluated.
- Merge all three documents and make the Values in the *Values and Ethics* document universal in health research, this would stop researchers skipping over them.
- There has to be a way to invest so that researchers have a sense of responsibility to 'tick the box' and also create a sense of accountability.

Keeping Research on Track

- Shorten it a bit, and use as the basis of an electronic resource.
- Greater emphasis is needed on translating research back to communities.
- Greater need for capacity building and feedback.

Other Suggestions for improvements

Participants expressed a need for:
- Better mechanisms for monitoring how research is going: 'How do we know researchers are doing what they said they would do'?
- HRECS need to be resourced to make sure they make the best decisions.
- A foreword in the *Values and Ethics* document explaining the history of Aboriginal health research.
- Both documents need to be more concise and simpler and could be living documents that are updated on a more regular basis.
- Define better difference blindness as this is not well understood.
- More case studies across a range of health research areas that focus in on how the values were addressed.
- Add in a glossary of Aboriginal terms.
- Explicit statements around reimbursement meeting part of reciprocity.
- Look for capacity building (Indigenous PhD and Masters) in research proposals.
- Provide guidance for international researchers and students.
- The documents should all refer to each other (*National Statement*, *Values and Ethics* and *Keeping Research on Track).*

Emerging issues

- Electronic health records.
- Protocols for bio banks and genetic research.
- Consistency of ethics assessment across jurisdictions.
- Multiple ethics applications.
- Intellectual property.
- Academic and community writing – who are the authors?

'Researching Right Way' Thursday Island consultation notes:

Stakeholder Experiences of using the NHMRC guidelines *Values and Ethics* and *Keeping Research on Track.*

g.   Community experiences of research and ethics processes

- Most health research ethics processes for the Torres Strait are approved through the Cairns Base Hospital ethics committee. The region is establishing a research governance processes, but this is in its early stages. There is now a research governance officer on Thursday Island. All research must go through this person for site specific approvals. Approval is usually through the health service General Manager. Participants indicated that this approval process may or may not involve consultation with local Torres Strait Islander people.

Community experience of the research process

- There are no community based health research approval processes in Queensland. Initially the research must go to the ethics committee at Brisbane (QLD Health) and if the research is to be undertaken in Cape York or Thursday Island, the research protocol is referred to the Cairns base ethics committee. There is an Aboriginal/Torres Strait Islander person on this committee. Once approved through this committee, the protocol must receive site specific approval (SSA) at the local health service where the research is proposed.

- On Thursday Island there may not be a Torres Strait Islander person involved in assessing the research protocol. No participant at the workshop was aware of either NHMRC documents, but did refer to the Torres Strait Regional Authority (TSRA) cultural protocols that include references to conducting research with Torres Strait Islander people.

- Participants stated at the workshop that there would be value in re-establishing a system that was in place not too long ago. That system was a consumer and community advisory group that was associated with the hospital and health system on the Island. Research protocols could be vetted by this group and they could act as a central point of contact.

- One of the main concerns of participants was the lack of ability to determine which health issues were prioritized in the research agenda and that a better system would

be to ask the community what health issues required research attention. As it is at the moment, research priorities are determined at the aggregate level nationally and communities must address national priorities for research funding. If local or regional issues fall outside this there is no way to put in a proposal for research for funding. It was suggested that NHMRC needs to have a community based funding round where communities can determine health research priorities and have researchers work with communities around those health issues (local and regional targeted calls for research).

- Another major issue raised by participants was the lack of feedback to communities. Of the numerous health research projects conducted in the Torres Strait only two were remembered as feeding back the results of the research to the local community.

- One of the major governance issues that affected research and community awareness of research was the abolishment of the Torres Strait Islander Health Council with the new Queensland government. This reduced the ability for local community involvement in health services (including knowing what health research was going on).

Researcher experiences of the research process

- Researcher user guide (RUG) Office of Health and Medical Research, Queensland Health

There is a single ethics review process for Queensland:
http://www.health.qld.gov.au/ohmr/html/regu/for_researcher.asp

- The researcher present at the workshop stated that the ethics process was quite detailed, complex and could become quite long depending on the number of sites proposed for the research. An example was provided on how consideration was not given to addressing the six values in the *Values and Ethics* document.

- The research described by the researcher intended to look at perceptions of hospital acquired infections. As the focus was on the acquired infections, the research team decided that addressing the six values was not required because all people were eligible to participate in the research and that the focus of the research was not on Aboriginal or Torres Strait Islander people alone. Given the locale of the research (Cape York and Torres Strait) it was obvious that the majority of participants would be Aboriginal and Torres Strait Islander people. This research was approved by a number of sites in the Cape and on Thursday Island. The process for approval in each of the sites was through the Directors of medical services, the finance areas (to ensure minimal financial impacts) and health centre managers on the outer islands.

Suggestions for improvements

Participants expressed a need for:

- Greater promotion of the *Values and Ethics* document and *Keeping Research on Track*.
- Training of new researchers in community protocols including situations of avoidance protocols.
- Participants described a process with the Central Australian Rural Practitioners Association (CARPA) manual; how this was largely taken up and how this process could be used to influence greater awareness of the *Values and Ethics* document and *Keeping Research on Track*.
- Alternative methods for dissemination are needed including DVD, video, social media and web based approaches including through systems such as rural health education foundation specific projects.
- Language was an issue identified as the *Values and Ethics* documents was described as too academic and needed to be reworded by a 'normal' person.
- Consistency between the National Ethics Application Form (NEAF) and *Values and Ethics* documents.
- A Thursday Island ethics sub-committee to be established and a process to identify appropriate representation on this committee.
- Establishment of a process where community driven health research priorities can be developed and funded by NHMRC.
- Feedback to the community should be mandatory and a way that the community understands.

APPENDIX 4: STAKEHOLDER SURVEY

Example of overall version attached as PDF.

- Press Advertisement – the Koori Mail, Torres Strait News
- Several editions of the Lowitja Institute fortnightly e-Bulletin (subscriber audience of approximately 2,300
- Posters printed and distributed for display in Aboriginal Medical Services
- Radio broadcast through National Indigenous Radio Service s, eight announcements over preceding week, in each targeted locations: Hobart, Broome, Darwin, Alice Springs, Cairns, Torres Strait Island
- Networking and wod of mouth