Explanatory material: public consultation on the revised Aboriginal and Torres Strait Islander research ethics guidelines

The following guidelines are currently under review:

- Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research 2003 (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).

Two revised drafts have been developed:

- Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders
- Keeping research on track II.

What is the scope of the proposed changes?

The draft Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders is a revised version of Values and Ethics and has undergone significant revision. It provides information about designing and conducting ethical and culturally appropriate research, and details six core values to ensure that all human research undertaken for Aboriginal and Torres Strait Islander Peoples and communities:

- respects the shared values of Aboriginal and Torres Strait Islander Peoples
- is relevant for Aboriginal and Torres Strait Islander priorities, needs and aspirations
- develops long-term ethical relationships among researchers, institutions and sponsors
- develops best practice ethical standards of research.

The draft Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders is primarily for researchers and Human Research Ethics Committees, although research participants and other stakeholders may also find it useful.

The draft Keeping research on track II is a revised version of Keeping Research on Track, but as there were minimal revisions the title has been retained. Keeping research on track II is primarily for research participants and communities, and provides information on how to apply and demonstrate the six core values as outlined in Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders.

The guidelines are intended to complement each other and should be used in conjunction. The scope of both draft guidelines has been broadened to cover research across all disciplines.

What is the rationale for the proposed changes?

In 2013, NHMRC commissioned an evaluation of Values and Ethics and Keeping Research on Track to inform their revision. This evaluation was undertaken by the Lowitja Institute, in conjunction with the Australian Institute of Aboriginal and Torres Strait Islander Studies. The evaluation was conducted throughout July–October 2013, and included extensive consumer engagement via consultation and workshops held in all states and territories. The evaluation report and accompanying literature review are available on NHMRC’s website.

Both guidelines have been revised to align with feedback provided during the evaluation and to update their content. The six core values described in the guidelines have been retained and applying these values will ensure...
that research conducted with or for Aboriginal and Torres Strait Islander Peoples and communities, or their data or biological samples, is ethically sound.

What type of feedback is being asked for?

Comments on any aspect of the guidelines are welcomed. In addition, there are several specific questions on which feedback is being sought. These questions are provided below. Submissions should not be restricted to these questions and all elements of the draft guidelines should be considered when preparing a submission. General comments as well as issues that relate to particular parts of either guideline are encouraged.

What will happen when the public consultation period is over?

Once the public consultation period has closed, all submissions will be considered by the Indigenous Research Ethics Guidelines (IREG) Review Working Committee, and feedback will be incorporated into the guidelines. A final version of the guidelines will then be submitted to relevant NHMRC committees for review, before consideration by NHMRC Council. Both guidelines will be prepared for publication, including design and layout, prior to their final release.

All non-confidential submissions will be published on the NHMRC website towards the end of the review, once all administrative and committee processes have been finalised.

Specific questions for public consultation

1. The previous guidelines focused on health research only and the scope of the revised guidelines has been broadened to cover research across all disciplines.
   - Is this broader scope adequately reflected in both guidelines?

2. Information about intellectual property has been included in both of the revised drafts.
   - Are the amount and strength of intellectual property information provided in each draft adequate?

3. Consideration is being given to including case studies as supplementary material for one or both of the revised drafts:
   - Should a case study about intellectual property be included?
   - If a case study about intellectual property was included, what are some good examples of case studies in this area?
   - What other topics would case studies be useful for?
   - What are some good examples of other case studies?

Introductory and historical context information

Once the public consultation period has finished and the committee consideration processes have been completed, the final guidelines will be released. At this time, it is proposed that some introductory, historical and contextual information that was previously provided in the guidelines will be placed on NHMRC’s website. This information was not included in the revised drafts in the interests of reducing overall volume. Instead, placing this information on NHMRC’s website will ensure that all users have access to it. This content will include the historical context of the relationship between Aboriginal and Torres Strait Islander Peoples and the conduct of research; guidance on how to use the revised drafts; the development of the revised drafts; and links to further resources. A draft of this content is provided in a separate document as background material.

Key changes

The key changes in the revised drafts are listed in the tables below.
## KEY CHANGES

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<th>Revised guideline</th>
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### Background (p.1–5):
- Introduction
- Context
- The approach to writing these guidelines
- Ethical relationships
- Integrating written guidelines with the development of ethical relationships

### Introduction (p.5–9):
- Role of the Ethical Guidelines
- Related principles
- Scope of the Ethical Guidelines
- Intended audience
- Research agreements
- Intellectual property

Information about the context and development of these guidelines has been updated and will be placed on NHMRC’s website as the landing page for the final guidelines when they are released.

### The Guidelines – Coverage (p.7–8)

Information now included under:
- Role of the Ethical Guidelines (p.6)
- Scope of the Ethical Guidelines (p.8)

### The Guidelines – Values and ethics (p.7–20)

The six core values (p.10–19):
- spirit and integrity
- cultural continuity
- equity
- reciprocity
- respect
- responsibility

Descriptions of all values have been updated and two values have updated names (cultural continuity replaces survival and protection; equity replaces equality). More practical ways of demonstrating each value have been provided and relevant sections of the *National Statement on ethical conduct in human research 2007* are hyperlinked.

Language has been simplified and clarified to assist understanding.

### Appendix 1: Development of the guidelines (p.21–22)

Appendix 1: Expert working committee (p.20)

### Appendix 2: Suggested application of the guidelines (p.23–24)

Some information has been moved to the Introductory sections and some has been moved to the draft revised *Keeping research on track II*. 
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### Introductory information (p.1–7)
- Making research work for us
- Joining in the research journey: a success story
- What are human research ethics?
- Getting on track

Introductory information (p.4–6)
- About this resource
- Intended audience
- Research agreements
- Starting a research journey

Introductory information has been updated. Information about ethics applications to Human Research Ethics Committees is on p.16.

### Our most important values (p.8–9)
- spirit and integrity
- reciprocity
- respect
- equality
- survival and protection
- responsibility

The six core values (p.7–8)
- spirit and integrity
- cultural continuity
- equity
- reciprocity
- respect
- responsibility

All values have been updated and two values have updated names (cultural continuity replaces survival and protection; equity replaces equality).

### Our rights to participate in research (p.10–14)

Rights about participating in research (p.9–13)

Information about rights has been updated and expanded upon.

### Intellectual property (p.14)

Intellectual property and copyright (p.12–13)

More detail is provided about the importance of intellectual property and copyright considerations. Provides references to the Australian Institute of Aboriginal and Torres Strait Islander Studies and Australia Council for the Arts guidelines for further and more specific information.

### The eight steps of the research journey (p.15–27)
1. Establishing relationships
2. Conceptualisation
3. Development and approval
4. Data collection and management
5. Analysis
6. Report writing
7. Dissemination
8. Learning from our experience

The eight steps of the research journey (p.13–30)
The eight steps have been retained with some updates to content and language.

### Overview of community involvement (p.28–29)
- the eight steps
- researcher's tasks
- community/organisation involvement

Table 1: a checklist of the eight steps research process (p.14-15)

Outlines the eight steps, researcher’s tasks and community/organisation involvement with updated language.
### About research and researchers (p.30–33)
- common types of research
- ways of starting research
- finding out about researchers
- issues with ‘new’ researchers

Some of this information has been incorporated into the Rights about participating in research section (p.9–13) or more logically aligned with the eight steps of the research journey:
- What are common types of research? (p.22)

### Further reading (p.34–35)

Further resources (p.31)

When the finalised guidelines are released, some introductory, historical and contextual information will be placed on NHMRC’s website as the landing page for the final guidelines. Links to further resources will also be available.

### Glossary (p.36–39)

Glossary (p.32–34)

Most terms have been retained and some new terms have been added.

### Helpful organisations (p.40–41)

Further resources (p.31)

When the finalised guidelines are released, some introductory, historical and contextual information will be placed on NHMRC’s website as the landing page for the final guidelines. Links to further resources will also be available.