

Introduction to Research

MODULE THREE



Slide 1 – Module Two: Effective Research Collaborations

Before you start on any study you will need to consider the ethical implications of your research. Module three discusses some important values and ethical considerations which should be considered and if appropriate, the types of issues that many ethics applications will require.

Module Three

Developing an Ethics Application

Study Guide: Chapter Three

Slide 2 – Do I need ethics approval?

The exceptions to this rule are:

- using data already in the public domain,
- collecting administrative information specifically for making improvements to processes and procedures,
- developing teaching and learning resources; or
- collecting information for quality assurance or audit purposes

and

- the information is owned by and collected within your organisation; and
- the information or the outcomes of any manipulation of this information is not presented to or published for use by any other individual or body external to your organisation.

Do I need ethics approval?

Almost any research activity that involves human participation is considered human research and will therefore require an application to relevant ethics committees.

Slide 3 – Which ethics committee?

A list of Australian ethics committees that are endorsed by the National Health and Medical Research Institute can be found at <https://www.nhmrc.gov.au/health-ethics/human-research-ethics-committees-hrecs/list-human-research-ethics-committees> .

While universities and most research institutes usually have strict guidelines around seeking approval from not only their internal ethics approval but also where appropriate, Aboriginal and Torres Strait Islander specific committees before commencing the research, consultants may not always adhere to the same requirements. We suggest that these approval processes are essential and necessary in all instances to ensure the rights of participants and you as a collaborating party are protected.

Which ethics committee?

There are a number of human research ethics committees in Australia, each with their own process and timelines for submitting, reviewing and responding to ethics applications.

<https://www.nhmrc.gov.au/health-ethics/human-research-ethics-committees-hrecs/list-human-research-ethics-committees>

Slide 4 – Ethical values and standards

Rather than one set of ethical values, research involving Aboriginal and Torres Strait Islander peoples need to consider a range of issues which could be thought of as a hierarchy. If you need to apply to more than one ethics committee it may be beneficial to consider using the National Ethics Application Form (NEAF). The benefit of the NEAF is that you will only need to complete the ethics application once. The disadvantages are that not all ethics committees accept a NEAF application and because the form attempts to capture everything any ethics committee might want to know, it is quite lengthy.

Ethical values and standards

Context specific values, standards and guidelines - for example the Wardliparingga Accord which extend the national guidelines

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

National Statement for Ethical Conduct in Human Research (NHMRC 2007)

Slide 5 – As a start...

At a minimum, the National Health and Medical Research Council (NHMRC) has developed the '*National Statement for Ethical Conduct in Human Research*' [15] which includes a set of core values which must be considered and addressed **when conducting all research** involving human participants.

Research Merit and Integrity

This value includes ensuring the research methods are appropriate, are based on a thorough study of the current literature, and designed to ensure respect for the participants. Research should also be conducted by appropriate qualified and experienced researchers and use facilities and resources appropriate for the research. Importantly, researchers must be committed to searching for knowledge and understanding, following recognised principles, conducting research honestly and disseminating and communicating results

Justice

This value includes ensuring the inclusion of participants, the process of recruiting and the distribution of benefits is fair. In addition, there should not be an unfair burden on participation.

Beneficence

This value includes ensuring the benefit of the research justify the risks of harm to participants and where there is no benefit, the risks to the participants should be lower than would be ethically acceptable. In addition, researchers are responsible for designing the study to minimise harm, telling participants about both the benefits and risks and ensuring the welfare of participants.

Respect

This value includes respect for human beings for their intrinsic value and respect for the individuals' right to confidentiality and privacy.

As a start.....

- Research merit and integrity
- Justice
- Beneficence
- Respect

Slide 6 – In addition...

The 'Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research' and the companion document 'Keeping research on track. A Guide for Aboriginal and Torres Strait Islander peoples about health research ethics' provide the next important level in the hierarchy of ethical values and standards. These two documents, which were developed in collaboration with Aboriginal and Torres Strait Islander communities, identify six core values which Aboriginal and Torres Strait Islander societies see as essential for conducting research involving Aboriginal and Torres Strait Islander peoples.

Spirit and Integrity

This is the most important value that joins all our Aboriginal and Torres Strait Islander peoples' values together. The first part, Spirit, is about the on-going connection (continuity) between our past, current and future generations. The second part, Integrity, is about the respectful and honourable behaviours that hold Aboriginal and Torres Strait Islander values and cultures together.

Reciprocity

Our way of shared responsibility and obligation is based on our diverse kinship networks. This process in our communities keeps our ways of living and family relationships strong. These responsibilities also extend to the care of the land, animals and country and involve sharing benefits from the air, land and sea, redistribution of income, and sharing food and housing.

Respect

Respect for each other's dignity and individual ways of living is the basis of how Aboriginal and Torres Strait Islander peoples live. Within our cultures, respect strengthens dignity, and dignity strengthens respect. A respectful relationship encourages trust and co-operation. Strong culture is built on respect and trust, and a strong culture encourages dignity and recognition, and provides a caring and sharing environment.

Equality

Aboriginal and Torres Strait Islander peoples recognise the equal value of all individuals. One of the ways that this is shown is in our commitment to fairness and justice. Equality affirms and recognises Aboriginal and Torres Strait Islander peoples' right to be different.

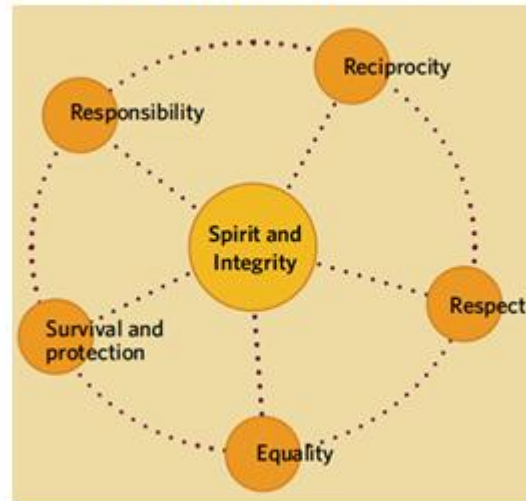
Survival and protection

We continue to protect our Aboriginal and Torres Strait Islander cultures, languages and identity. Recognition of our shared cultural identity, which is based on our shared values, is a significant strength.

Responsibility

All Aboriginal and Torres Strait Islander communities recognise the same most important (core) responsibilities. These responsibilities involve country, kinship bonds, caring for others, and the maintenance of cultural and spiritual awareness. The main responsibility is to do no harm to any person, or any place. Sometimes these responsibilities may be shared so that others may also be held accountable.

In addition.....



Slide 7 – And also...

There are also values and guidelines developed at state, regional and/or local levels. You could check with the state peak Aboriginal Community Controlled Organisation or the National Aboriginal Community Controlled Organisation to find out what could apply in your particular context. For example, in response to a call from Aboriginal communities and researchers within South Australia, Wardliparingga Aboriginal Research Unit has developed a set of nine principles based on national and international best practice frameworks and guidelines for conducting research with Indigenous peoples.

PRINCIPLE 1. PRIORITIES: Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability.

Principle 2. INVOLVEMENT: The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research.

Principle 3. PARTNERSHIP: Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures.

Principle 4. RESPECT: Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge.

Principle: 5. COMMUNICATION: Communication must be culturally and community relevant and involve a willingness to listen and learn.

Principle 6. RECIPROCITY: Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.

Principle 7. OWNERSHIP: Research should acknowledge, respect, and protect Aboriginal intellectual property rights and ensure transparent negotiation of Intellectual Property use and benefit sharing.

Principle 8. CONTROL: Research must ensure the respectful and culturally appropriate management of all biological and non-biological research materials.

Principle 9. KNOWLEDGE TRANSLATION AND EXCHANGE: Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice.

And also.....

**The South Australian
Aboriginal Health
Research Accord**

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

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

Slide 8 – The ethics application

While each ethics committee will have a list of information that they require in order to assess an application, in general ethics committees will be interested in this information:

- name and affiliations of investigators,
- aims, objectives as well as primary questions and/or hypotheses,
- significance of the research,
- how the participants and/or the population more generally will benefit from the research,
- who will participate and how will they be contacted and invited to participate,
- how you will ensure that consent from participants is informed and voluntary,
- how the study will be undertaken including how the data will be collected and analysed (see Chapter Four); and
- how the findings will be disseminated.

The ethics application

- Name and affiliations of investigators
- Aims, objectives and primary questions
- Significance and benefits of the research
- Who will participate & how will they be invited
- How will informed and voluntary consent be obtained
- How the study will be undertaken
- How the findings will be disseminated

Slide 9 – You will also need to...

If you are intending to invite Aboriginal and Torres Strait Islander people to participate in research you may also be asked to:

- explain how you have consulted with the community or communities,
- demonstrate that you have broader community or communities' support; and
- identify opportunities for strengthening the capacity of Aboriginal and Torres Strait Islander people.

You may also be asked to specifically address Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (<https://www.nhmrc.gov.au/guidelines/publications/e52>).

You will also need to....

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- demonstrate that you have broader community or communities' support; and
- identify opportunities for strengthening the capacity of Aboriginal and Torres Strait Islander people.

Slide 9 – Research collaborations

Key messages from Module Three include:

- There are a range of values which must underpin the conduct of ethical research including:
 - National Statement for Ethical Conduct in Human Research
 - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research
 - State, regional and/or local level ethical guidelines
- Ethics committees review your proposed research to ensure that it meet all relevant ethical values.
- Approval must be obtained prior to commencing any research.

Key messages

- There are a range of values which must underpin the conduct of ethical research including:
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 - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research
 - State, regional and/or local level ethical guidelines
- Ethics committees review your proposed research to ensure that it meet all relevant ethical values.
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