

# The University of Queensland Guidelines for Ethical Review of Research Involving Humans

As part of the design process for any research project involving human subjects or human-related materials, University of Queensland researchers must investigate the need for ethical clearance and obtain it when required. The following pages outline the procedures for applying for approval.

The approach of the University of Queensland Human Research Ethics Committees (HREC) is to encourage members of our institution to behave in an informed and responsible manner in the conduct of their research and for the committees to support and facilitate this research so that ethical principles and conduct in relation to human experimentation are always paramount. We wish this approach to be reflected in our administrative procedures. We want to ensure that the University is able to undertake this whole process of ethics review so that those who volunteer to be participants in research have their rights and needs respected and protected.

Researchers should use this document in conjunction with the National Statement on Ethical Conduct in Human Research, which is the primary set of guidelines for ethical review (National Statement).

UQ Human Ethics Website: http://www.uq.edu.au/research/integrity-compliance/human-ethics

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# **SECTION ONE – INTRODUCTION**

## Who Should Apply?

These guidelines apply to **all** research involving human participation in its many forms. This includes interviews, completion of questionnaires, observations, and use of already collected data, samples, and materials.

Academic and General Staff, and Postdoctoral Researchers should submit a completed form to the Ethics Coordinator for review by one of the Human Research Ethics Committees (HREC) of the University, after consultation with the *National Statement on Ethical Conduct in Human Research (National Statement)*, the UQ Guidelines, their supervisors and peers.

Students undertaking "low risk" (ie, where the only foreseeable risk is one of discomfort) projects at Undergraduate, Honours, Postgraduate Diploma, Coursework Masters, Research Masters, or PhD level should submit a completed application form to their respective School-level ethics reviewer or panel (where applicable) for review, after consultation with the *National Statement* and UQ Guidelines, their peers and supervisors. The School-level reviewer or panel may decide to refer an application for central review by a HREC if appropriate.

Please note that School-level review may require submission on a School specific application form and it is the responsibility of the student to acquire the correct forms for submission.

Please refer to Section Two of these Guidelines on School Level Ethics Committee Review.

# SECTION TWO – APPLICATION PROCEDURES

## Committee structure at UQ

The human ethics review process at the University of Queensland is conducted by one of the two sub-committees of the principle Human Experimentation Ethical Review Committee (HEERC). The sub-committees are:-

- Behavioural & Social Sciences Ethical Review Committee BSSERC
- Medical Research Ethics Committee MREC

The Committees are duly constituted HRECs in accordance with the requirements of Australian Health Ethics Committee (NHMRC).

#### **Research Not Requiring Review**

There are no categories of human research which are exempt from review.

Data, samples, and materials collected or obtained without UQ ethics approval (and any other relevant approvals) can not be used for research purposes.

#### **School Level Ethics Committee Review**

The University of Queensland operates a peak ethical review committee, the Human Experimentation Ethics Review Committee (HEERC), and 2 ethics sub-committees, the Behavioural & Social Sciences Ethical Review Committee (BSSERC), and the Medical Research Ethics Committee (MREC).

HEERC is principally a committee of broad policy development and of appeal, while its 2 sub-committees consider research protocol applications at first instance in addition to policy development specific to the usual types of research protocols considered by them. These 3 institutional ethics committees are duly constituted under the Australian Human Ethics Committee (AHEC) which is a committee of the NHMRC.

#### Ambit of School Level Ethical Review Committee

Schools are encouraged to establish their own ethical review mechanism (if they have not already done so) to review research protocols from their students up to the level of, and including, PhD.

School level ethical review committees should consider research projects up to the level of, and including, PhD, in the following circumstances:

- 1. where the project involves no more than *low risk* (research is "low risk" where the only foreseeable risk is one of discomfort), and
- 2. the school committee considers that it does not require institutional review (by either BSSERC or MREC).

Projects involving commonly accepted professional or clinical practices and procedures may be assessed by a school ethics committee to be low risk.

The function of school committees is not the review of protocols involving more than low risk. School committees are not constituted under, or registered with, AHEC, nor should be so constituted or registered.

Protocols involving a higher risk will properly fall within the jurisdiction of one of the institutional ethics committees.

If the school committee considers the risk to be above the prescribed level, or considers it prudent in the circumstances, for an institutional ethics committee to review the protocol (e.g., because the research is of a particularly sensitive nature or the study population is a particularly vulnerable group), then the application may be referred to the appropriate institutional committee, i.e., BSSERC or MREC. Alternatively, the school committee may require the protocol to be amended in order to reduce the risk to within the threshold level.

Irrespective of the level of risk involved, research of a kind falling under the following chapters of the *National Statement* must be reviewed by one of the institutional ethics committees:-

- 1. Deception and concealment (Chapter 2.3.4)
- 2. Interventions and therapies, including clinical and non-clinical trials, and innovations (Chapter 3.3)
- 3. Human embryos and embryonic stem cell lines (Chapter 3.4)
- 4. Human genetics (Chapter 3.5)
- 5. Women who are pregnant and human foetus (Chapter 4.1)
- 6. People highly dependent on medical care who may be unable to give consent (Chapter 4.4)
- 7. People with a cognitive impairment, an intellectual disability, or a mental illness (Chapter 4.5)
- 8. People who may be involved in illegal activities (Chapter 4.6)
- 9. Aboriginal and Torres Strait Islander peoples (Chapter 4.7)

#### Structure of School Level Ethical Review Committee

It is open to individual schools to determine the specific structure and processes of their internal ethical review mechanism. Schools may, for example, wish to establish a committee comprising several staff members who have sufficient seniority to assess the potential risks involved in the protocol. These staff members may be drawn from the current membership of an existing research or postgraduate committee, and must be familiar with the *National Statement* and have an understanding of the ethical issues that can arise in the research under review.

Since school level committees are not AHEC registered, it is not necessary for it to have the broad range of membership representation that is required for an AHEC registered committee.

The school committee shall report to either the Head of School, or their school academic/research committee, as appropriate.

#### **School Level Application Form**

A standard application form for review by an institutional committee (BSSERC or MREC) is available as a document download from the UQ Human Ethics Website. Schools may wish to adopt this form for use in protocol submissions to their committees, as an alternative to developing their own individualized form.

School committees should maintain records of protocols reviewed.

It is expected that the research student's supervisor would carefully work with the student in completing the application form.

#### Additional Notes:

1. Where Schools do not currently have an operating ethics committee, they are encouraged to establish one, but to refer applications to the Institutional Committees when required.

2. Authority to approve research ethics submission is granted through the Human Experimentation Ethical Review Committee (HEERC) and its various sub-Committees. Principles of the *National Statement* and these guidelines must be adhered to.

3. The Chairperson of the School level ethics committee can refer protocols to the relevant University sub-Committee for clarification or advice at anytime, as well as deem that the risk on a submitted protocol is too great for their Committee to approve, and submit to the Ethics Officer for consideration by one of the sub-Committees.

4. Proposals by research academics (ie, non-student) must be submitted to the Institutional Ethics Committees (i.e., BSSERC or MREC).

#### Students' submissions

5. Students up to and including PhD level, provided the risk criteria are satisfied, should submit a completed application form to their respective School ethics committee for process, after consultation with these guidelines, their peers and supervisors.

6. It is the **student's** responsibility to become acquainted with the review process and any specific requirements of submission to the School ethics committee . (eg closing dates, number of copies,)

7. The School ethics committee may elect to have their own application form and it is the responsibility of the students to acquire the correct form for submission.

8. Students should be aware that the School ethics committee Chairperson may elect to submit their proposal for consideration to the appropriate University sub-Committee for advice.

## Human Research Ethics Committee Review Procedures

These Guidelines will assist the researcher to ascertain whether their project requires expedited or full committee review. All researchers are reminded that work involving human participants/subjects/data/samples/materials **must not** commence until the appropriate advice has been issued from the approving UQ ethics committee. It is the researcher's responsibility to ensure that they obtain the correct clearances (including any relevant external clearances) before such work commences. It is also the researcher's responsibility to contact the Ethics Coordinator to inquire about the progress of their clearance.

All applications for review require completion of the Human Ethics Application Form:-

and attaching copies of any associated documents such as:

- questionnaires specifically developed or amended for the proposed project,
- gatekeeper approvals,
- other ethics approvals,
- protocol document, if applicable, and
- any Participant Information Sheets and Consent Forms to be used.

For projects that are part of any contractual work (eg, medical or clinical trials, consultancies) the original indemnity forms should also be submitted.

If the researcher has additional information that they believe will assist in the review of the project, it should also be attached to the application form.

The Chief Investigator must ensure that the application form is clearly and correctly annotated as to which type of review is required on the form. The CIs must also read and sign the declaration on the application form, and where a supervisor is involved, obtain the Principal Supervisor's signature.

Expedited Review requires 2 (two) copies of all of the above documentation to be submitted. Papers should be stapled or clipped together.

Full Committee Review requires the original and 15 (fifteen) copies of **all** of the above documentation to be submitted. Papers should be stapled or clipped together in their sets.

The sub-committees may at times consider the review of applications for studies from organisations external to the University. Where these studies involve commercial organisations, a non-refundable administrative fee is charged. For more information, contact the Ethics Coordinator.

The completed application and its attachments should be sent to:

The Ethics Coordinator UQ Research & Innovation Cumbrae Stewart Building (72) The University of Queensland QLD 4072

#### **Please note the following:**

- 1. Applications will **not** be processed without the declaration section of the application form being completed correctly.
- 2. Confirmation of receipt of the application is issued to the researcher.
- 3. The Ethics Office will send advice of the approval to the Chief Investigator.
- 4. Any amendments made to the approved methodology, questionnaires, letters, consent forms and/or information sheets **must** be submitted to the Ethics Office attached to the Ethics Amendment Form. If the Researcher considers the amendments to be of a minor nature, only *one copy* of all documentation is required. Should the amendments be major and change the nature of the original approval to that now requiring full committee review, then the

appropriate application form should be completed, annotated with the original clearance number, 15 copies attached, and submitted to the Ethics Office for review.

- 5. All adverse events, incidents or complaints associated with the approved project **must** be reported to the Ethics Office within 12 hours, by completion of the Human Ethics Adverse Events Report Form. *Where the report is considered to be serious in nature the Researcher should cease all further work involving humans until further notice from the* Ethics Office *has been received*.
- 6. Annual Progress Reports will be sent to the Chief Investigator in January of each year.
- 7. Failure to comply with the Annual Progress Report **may** result in the suspension of the human ethics clearance for the named project, and jeopardize the completion of the proposed research.
- 8. As part of the clearance, the reviewing Committee has the right to audit all documentation and data, and the conduct, of the approved project at any time.

#### **Full Committee Review Procedures**

Full Committee Review entails the Researcher submitting sufficient copies of the completed application form (15 copies) and its attachments to the Ethics Office and these being sent to each member of the reviewing committee for comment. Members return a response to the Ethics Office and should consensus be reached, the file is submitted to the Chairperson for final approval prior to the next meeting. At the next meeting all projects that have received consensus approval are ratified by members.

Only projects that members feel require discussion are held over for the next meeting.

In this way, applications are considered on a continual basis, and Researchers are encouraged to submit their applications for consideration as soon as they are ready and need not align submission to a meeting date.

Should the members submit comments on the reviewed application, correspondence between the Ethics Office and the researcher will be entered into, with some comments sent back to members for their approval.

Once the committee members reach consensus, the Ethics Coordinator submits the *complete* file for final approval by the Chairperson. The original advice of final clearance is sent to the Chief Investigator.

The file is retained by the Ethics Office until expiry of the approval or an Annual Progress Report form is returned indicating that the project has completed.

Completed files are retained by the University for a minimum of seven years in accordance with NHMRC guidelines. Exemptions to this are the clinical trials where the files are retained by the University for a minimum of 15 years.

## **Expedited Review Procedures**

Expedited review is an application for ethical consideration by the Chairperson of the appropriate sub-Committee which:-

- meets all of the following conditions; and/or
- already holds an ethical clearance from a registered Human Research Ethics Committee (HREC)

In order to qualify for Expedited review a project must meet all of the following conditions:-

- 1. it must not involve any kind or any threat of risk of physical, material, psychological harm of or any distress or social discomfort to the subject of any kind whatsoever
- 2. the research must not involve questions or information which, if disclosed outside the research, could place the subject at risk of criminal or civil liability or damage reputation, financial standing etc. (examples: disclosure of sexual preference, questions about illegal behaviour, health status, etc.)
- 3. the research involves no more than "low risk" (research is "low risk" where the only foreseeable risk is one of discomfort)
- 4. The research must not be of a kind falling under the following chapters of the National Statement:-
  - Deception and concealment (Chapter 2.3.4)
  - Interventions and therapies, including clinical and non-clinical trials, and innovations (Chapter 3.3)
  - Human embryos and embryonic stem cell lines (Chapter 3.4)
  - Human genetics (Chapter 3.5)
  - Women who are pregnant and human foetus (Chapter 4.1)
  - People highly dependent on medical care who may be unable to give consent (Chapter 4.4)
  - People with a cognitive impairment, an intellectual disability, or a mental illness (Chapter 4.5)
  - People who may be involved in illegal activities (Chapter 4.6)
  - Aboriginal and Torres Strait Islander peoples (Chapter 4.7)

Where the research satisfies the above criteria **and** is supported by complete written confirmation of appropriate 'gatekeeper' approvals and/or anonymous questionnaires (where applicable), the researcher may apply for expedited review.

Alternatively, a submission may be considered for expedited review when the research project already holds approval from another AHEC registered HREC (eg. a Hospital Ethics Committee, University Ethics Committee).

In this instance and at his/her discretion, the Chairperson reserves the right to request full committee review, notwithstanding prior clearance by another HREC, if any aspect of the project such as procedure (eg. violation of privacy), subject population (eg, children, collectivities ) or consent process appear to him/her to warrant further scrutiny.

Expedited review **does not** exempt the researchers from submitting full details of the project to the appropriate University HREC for approval **prior** to commencement of the project, nor does it absolve the researchers from adherence to acceptable ethical standards as outlined in these Guidelines and the *National Statement*.

Researchers should be aware that any Participant Information Sheet approved by Expedited Review must still contain the University's Ethical Clearance Paragraph.

## **Complaints**

The HEERC has approved the use and wording of the University's Ethical Clearance Paragraph for inclusion in all Participant Information Sheets to be given to participants of research projects.

The University's Ethical Clearance Paragraph provides an avenue for the participants to contact an officer of the University who is not connected with the project, namely the Ethics Coordiantor, to discuss any concerns that may arise from their participation in the research.

This avenue of complaint is ideally recommended after the participant has discussed the issue/s with the Researcher/s, or where the participant wishes to address particular concerns with regard to the researchers themselves.

If negotiations through the Ethics Coordinator do not resolve the issue the matter is referred to the Chairperson of the approving Committee for further advice.

The Ethics Coordinator and the Chairperson have the authority to contact any professional assistance available to them within, or external to, the University of Queensland to assist in the resolution of the complaint.

Any legal matters are referred to the University's Legal Officer for advice.

The University's Insurance Manager may also need to be made aware of the matter.

The full membership of the approving Committee is made aware of any such matters at the next meeting.

Details of matters of a serious nature, that is sufficient to suspend the project, produce legal and/or insurance concerns are also made known to the Chairperson of the HEERC.

In addition to the above, a person wishing to make a complaint or an allegation of breach of *The Australian Code For The Responsible Conduct of Research* or research misconduct should refer to the Policy and Procedures Library (4.20.05).

#### **University of Queensland Ethical Clearance Paragraph**

The following paragraph is to be incorporated into **all** Participant Information Sheets given to participants in human research:

"This study adheres to the Guidelines of the ethical review process of The University of Queensland and the *National Statement on Ethical Conduct in Human Research*. Whilst you are free to discuss your participation in this study with project staff (contactable on .....), if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on 3365 3924."

### **Informed Consent**

The *Belmont Report*<sup>1</sup> originally established three standards that the informed consent process must satisfy to be "valid". That is, the consent process must inform the subject; it must ensure the subject comprehends the information provided; and, assuming each of the first two have been met, the subject can make a voluntary choice on whether to participate or not.

Thus the importance of the content, layout and use of information and consent forms for research involving humans cannot be stressed to highly. These are the documents by which proposed participants can gain an understanding of their involvement in the proposed project and the risks that they may incur by their participation.

The researcher has a duty to ensure that the participants are provided with sufficient information on the project for them to understand why the project is being conducted and what their involvement and risks will be. To do this adequately the researcher should ensure that the level of language used within these documents is directed towards a person of an 'average' comprehension and reading ability. Where possible all technical terms should either be eliminated or adapted to the 'average' comprehension level.

In cases of research involving children, young people, people with impaired capacity, or those in dependent relations, it may also be necessary to decrease the reading level of the document to less than that suggested. The researcher should take time to become aware of the comprehension levels of their intended subjects and adjust the documents' level of comprehension accordingly.

At a minimum, informed consent documents require the researcher to provide the participant with:-

- 1. the title of the project
- 2. the purpose of the proposed study
- 3. the expected duration of their participation in the study
- 4. a clear and precise description of procedures for their involvement
- 5. a clear and precise description of any foreseeable risks due to their involvement in the study (in quantitative form, if applicable)
- 6. a clear and precise description of any benefits from their participation in the study
- 7. disclosure of any appropriate alternative methods or treatments, in cases of clinical research
- 8. the method used to maintain their confidentiality and privacy, along with the security of the data once collected and stored
- 9. a statement providing details of provision of emergency medical treatment should an injury occur
- 10. a statement concerning any compensation or medical treatment should injury occur
- 11. a statement that their participation is voluntary and that they may withdraw at anytime without prejudice
- 12. a statement that advises what would happen to data already collected should they withdraw after commencing the project
- 13. the name and contact details of the appropriate person to answer any further questions they may have concerning their participation in the project
- 14. a statement on gaining feedback or results concerning either their individual involvement in the project or the completed study dependant upon the research context
- 15. inclusion of the University's ethical paragraph which provides participates with an avenue of complant should they feel they are not able to discuss their concerns with the researchers themselves.

All Participant Information Sheets must be on letterhead, and include the University's Ethical Clearance Paragraph.

The Participant Information Sheet should preferably be separate from the Consent Form. This enables retention by the participants of valuable information about the project and the researchers should they later wish to discuss any concerns.

The Consent Form is returned to the researcher after signing and stored as part of the project records.

In the cases of research involving children, young people, people with impaired capacity or those in dependent relations there should also be a signature gained from the parent or legal guardian, according to Queensland law granting consent for the person to participate.

#### Footnotes

1. *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, Department of Health, Education and Welfare Publication No (OS) 78-0012, US Government Printing Office, Washington, 1978

#### Risk

Harm is that which negatively affects the interests or welfare of an individual or collectivity.

Risk refers to the probability of harm.

Researchers have an obligation to safeguard the rights and welfare of all subjects involved in research, training, educational development and other activities where subjects are exposed to a risk that could be detrimental to their health or well-being. In those cases where risk may exist, even with informed consent, approval of a research project will be made only if the risk to the individual is clearly explained,, as is any potential benefit to the person (as in the case where an activity involves therapy, diagnosis, management, etc.).

The University of Queensland may be held responsible for physical or psychological injury to human subjects attributable to university-sponsored research, development, and related activities, to the extent that a liability exists under federal and state laws. Therefore, the obligation of researchers to conduct activities in a manner and at such locations as will assure the proximity of adequate medical attention if warranted, and to provide appropriate referrals of subjects to adequate facilities and professional attention, should subjects suffer physical, psychological or other injury, is of paramount importance when designing research involving human subjects.

The seriousness of a risk to subjects is a function of the magnitude of the harm and the probability of the harm. A risk may be serious or significant because it has a probability (even a low probability) of great harm (e.g., a low probability of death), or because it has a high probability of slight harm (e.g., a near certainty of physical discomfort or psychological distress).

The risks of participation in research may be part of the research design or may be a consequence of the research procedures, or both (e.g., the risks of an adverse reaction to an investigational drug are part of the research design, while the risk of hematoma from blood drawn in the research is not part of the design but a consequence of the research procedures). Risks may be a consequence of the methods of recording, maintaining, or reporting data, and they may be a consequence of methods of obtaining informed consent.

**Physical risks** include physical discomfort, pain, injury, illness or disease brought about by the methods and procedures of the research. A physical risk may result from the involvement of physical stimuli such as noise, electric shock, heat, cold, electric magnetic or gravitational fields, etc. Engaging a subject in a social situation which could involve violence may also create a physical risk

**Emotional and psychological risks** include the production of negative affective states such as anxiety, depression, guilt, shock, loss of self-esteem and altered behaviour. Sensory deprivation, sleep deprivation, use of hypnosis, deception or mental stresses are examples of psychological risks.

**Social risks** include alterations in relationships with others that are to the disadvantage of the subject, including embarrassment, loss of respect of others, labelling a subject in a way that will have negative consequences, or in some way diminishing those opportunities and powers a person has by virtue of relationships with others.

**Economic risks** include payment by participants for procedures not otherwise required, loss of wages or other income and any other financial costs, such as damage to a participant's employability, as a consequence of participation in the research.

**Loss of confidentiality risks**. In all research involving human subjects, confidentiality of identifiable information is presumed and must be maintained unless the investigator obtains the express permission of the subject to do otherwise, or in other limited circumstances. Participants have the rights to be protected against illegal invasions of their privacy and to preservation of their personal dignity. The more sensitive the research material, the greater the care that must be exercised in obtaining, handling, and storing data.

Legal risks exist when the research methods are such that the subject or others will be liable for a violation of the law, either by revealing that the participant or others have engaged or will engage in conduct for which the participant or others may be criminally or civilly liable, or by requiring activities for which the subject or others may be criminally or civilly liable.

## SECTION THREE – ADDITIONAL CONSIDERATIONS

# **Research Involving People with Cognitive Impairment, Intellectual Disability or Mental Illness**

Investigators should be aware of the regime established in Queensland in relation to persons with impaired capacity under the *Guardianship and Administration Act 2000*, including the role of the Queensland Civil and Administrative Tribunal. Special provisions also exist in relation to the approval of clinical trials under this legislation. Advice from the University's Legal Office may be required in such cases. Investigators should consult their supervisors in the first instance.

### **Research Involving Hospital Patients or to be Conducted in Hospitals**

Research involving hospital patients and their records will require review and approval by the relevant hospital ethics committee at first instance <u>before</u> submission to UQ Ethics Committee.

### **Research Involving Aboriginal and Torres Strait Islander Peoples**

The following commentary is provided only as an introduction to research involving indigenous peoples. In addition to the *National Statement*, researchers should refer to more detailed guidelines such as the "Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research" (NHMRC) and the "Guidelines for Ethical Research in Australian Indigenous Studies" (AIATSIS).

In assessing a research proposal involving study of Aboriginal and Torres Strait Islander individuals or communities, the appropriate HREC must be satisfied that:

- 1. In the preparation of the research proposal, the researcher has sought advice from the local communitycontrolled Aboriginal and Torres Strait Islander health service, agency or organisation (where appropriate).
- 2. The Aboriginal and Torres Strait Islander community, or appropriate community controlled agency able to represent the Aboriginal and Torres Strait Islander group which is the focus of research, has indicated that the research being proposed will be potentially useful to the community in particular or Aboriginal and Torres Strait Islanders in general, and will be conducted in a way that is sensitive to the cultural and political situation of that values and needs of that community.
- 3. The researcher has obtained written documentation of consent from the communities in which it is proposed to conduct research. In such circumstances, informed consent should be shown to have involved:
  - provision of information in a form accessible to community members and able to be readily understood by them. This information should have included details of the collection and analysis of data, and the drafting and publication of reports. It should also list any potential costs to the community as well as potential benefits;
  - face-to-face discussions with community groups and individuals concerned wherever possible;
  - the allowance of sufficient time for the community and the individuals concerned to assimilate and respond to the information offered;
  - demonstration of a process for obtaining free consent from individuals as well as written evidence of consent by the community-at-large;
  - provision of information to participants that consent may be withdrawn at any time.
- 4. Members of the Aboriginal and Torres Strait Islander community being studied will be offered the opportunity to assist in the research.

- 5. The researcher recognises the right of the community to request further information about aspects of ongoing research, and accepts that changes in research protocols, procedures or methodologies will require further negotiations with the community and consent for that change by the community or an agency nominated by the community. The appropriate HREC must also be notified and be given the opportunity to approve amendments to the research protocol.
- 6. In the case of health research, researchers are also advised to refer to "Values and Ethics: Guidelines for ethical Conduct in Aboriginal and Torres Strait Islander Health Research".

#### Ownership and publication of data

- 1. Following completion of data collection and analysis, and before any publication or presentation of this data, a summary of the findings will be reported to the community as a whole. Details of findings relevant to their health or well-being will be confidentially conveyed to individuals who participated together with counselling as appropriate.
- 2. If a researcher wishes to use the information or blood or tissue samples gathered in the course of research for any purpose other than that for which consent was obtained, further permission must be sought from the community.
- 3. The return of identifiable raw data, its destruction, or secure storage on completion of the research, should be negotiated with the community, or its nominated representative or agency, prior to the commencement of the research.
- 4. Results will not be published in a form which permits identification of individual subjects. Results which identify a particular Aboriginal or Torres Strait Islander community will not be published without permission from that community or from a community controlled agency able to represent that community.
- 5. Pictorial material will be made only with the consent of the local community, individuals (if surviving) depicted in the material, and will be handled in accord with their wishes and in line with cultural constraints.
- 6. Proper acknowledgement will be given to individuals and communities who took part in the research.
- 7. Wherever practicable, Aboriginal or Torres Strait Islander assistants who contributed to the research will be involved in the preparation of publications and will be acknowledged.
- 8. Should the media solicit comments from researchers, once their work is in the public arena, researchers should first seek the consent of the community concerned. All comments to the media should be sensitive and professional and should be restricted to the research issues under consideration.

#### Native title

- 1. Research conducted with indigenous communities, and/or on indigenous land or proposed land, and/or within indigenous regions of water, must take account of indigenous interests.
- 2. This may involve seeking a permit to conduct the research activities, and it is the researchers responsibility to ensure that all correct clearances, including permits, are obtained for the study before work commences. If there is any doubt about the proposed research and its connection to indigenous interests the researcher should contact the University's Aboriginal and Torres Strait Islander Studies Unit (ATSISU) on campus or the appropriate government department for clarification.

The Environmental Protection Agency, Cultural Heritage Branch has released the following information to the University of Queensland.

Requirement to consider indigenous interests and native title matters prior to undertaking certain research activities.

It is often a legal requirement to obtain a permit prior to undertaking certain research activities. Queensland and Commonwealth legislation requires that prior to issuing some of these permits, regard must be had to any indigenous interests in the area. The permits most often affected are:

- Permits to survey, excavate and collect under the *Aboriginal Cultural heritage Act 2003 (Qld)* and the *Torres Strait Islander Cultural Heritage Act 2003 (Qld)*,
- Research Permits under regulations of the Nature Conservation Act 1992 (Qld)
- Research Permits under regulations of the Marine Parks Act 2004 (Qld).

Researchers are also advised to contact the University's ATSISU for support.

#### **Contacting appropriate parties**

It is appropriate to discuss proposed research with indigenous people who have an interest in the land or waters where the research is to take place, prior to applying for a permit. This will allow them the opportunity to provide any advice or assistance they may wish to provide and to discuss any concerns they may have about the research. It should also prevent unnecessary delays following the issue of a notification by the Government Department.

#### **Research Involving Ionising Radiation**

The UQ researcher is advised to contact the University of Queensland's Radiation Officer.

# Acknowledgments

This document is released under the authority of the Vice-Chancellor, through the Human Experimentation Ethical Review Committee, UQ Research & Innovation, University of Queensland, Queensland, 4072, Australia.

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