

The role of an independent Research Ethics Committee: Keeping researchers honest

Chrissy Grant

Chairperson, AIATSIS Research Ethics Committee

Firstly, let me pay my respects to the elders and acknowledge the Ngunnawal people on whose land we meet today. My presentation is focused on providing information for researchers – not only to keep them honest but allowing them to maintain their integrity with the Aboriginal and Torres Strait Islander peoples of Australia where they are the subject of this research.

Background

Australian Institute of Aboriginal And Torres Strait Islander Studies

The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) is the premier national, multidisciplinary research institution focusing on Aboriginal and Torres Strait Islander studies. It has a special mission to assemble this knowledge and increase understanding of Indigenous cultures and societies within Australia and internationally.

AIATSIS has been providing a grant program for many years since its establishment for research into Aboriginal and Torres Strait Islander peoples' lifestyle, past and present. AIATSIS funds research in a wide range of areas in Aboriginal and Torres Strait Islander studies such as: history (including family and community history), politics, law, public policy, health (social, cultural and environmental aspects), biological sciences, education, Indigenous knowledge systems, linguistics, social anthropology, archaeology and the arts.

In addition to the Council and the Executive Board of Management, AIATSIS's governance is supported by a number of committees. Two of those committees dealing specifically with grants include the Research Advisory Committee (RAC) and the Research Ethics Committee (REC).

The AIATSIS REC was established by Council in 1996. The REC meets to review the ethical content of grant applications in line with the online grant guidelines and its own *Guidelines for Ethical Research in Indigenous Studies* (AIATSIS 2002), which are considered a national standard in Indigenous research.

National Health and Medical Research Council (NHMRC)

In 2005 the AIATSIS REC applied for accreditation with the National Health and Medical Research Council (NHMRC). In 2006 the AIATSIS REC became an affiliate of the NHMRC. Through this, as well as at the direction of AIATSIS Council, the REC has obligations and responsibilities to report on its activities.

The *National Statement on Ethical Conduct in Research Involving Humans 1999* (the *National Statement*) stipulates that organisations that conduct research involving humans should ensure that such research is subjected to rigorous ethical review by a properly constituted and operating Human Research Ethics Committee (HREC). All HRECs should be structured and function in accordance with the *National Statement* and related NHMRC Guidelines.

The AIATSIS REC had to ensure that they meet the National Statement and this required the REC to follow a number of procedures. These are in effect, the 'terms of reference' of the REC.

Guidelines for ethical research In Indigenous studies

In 1999, the REC held workshops to develop new guidelines intended for research sponsored by AIATSIS and to use in their assessment of grant applications and research proposals. The *Guidelines for Ethical Research in Indigenous Studies* (the *Guidelines* – AIATSIS 2002) expresses the principles of ethical research and are founded on respect for Indigenous peoples' inherent right to self-determination, and to control and maintain their culture and heritage. It is considered that these principles are not only a matter of ethical research practice but of human rights.

Guideline Principles

The *Guidelines* include a statement of the principles of ethical research followed by an explanation of each principle, accompanied by some practical applications.

In summary the three (3) principles related to Ethical Research include:

- A. **Consultation, negotiation and mutual understanding** – consultation, negotiation and free and informed consent are the foundations for research with or about Indigenous peoples; the responsibility for consultation and negotiation is ongoing; and consultation and negotiation should achieve mutual understanding about the proposed research.
- B. **Respect, recognition and involvement** – Indigenous knowledge systems and processes must be respected; there must be recognition of the diversity and uniqueness of peoples as well as of individuals; the intellectual and cultural property rights of Indigenous peoples must be respected and preserved; and Indigenous researchers, individuals and communities should be involved in research as collaborators.
- C. **Benefits, outcomes and agreement** – the use of, and access to, research results should be agreed; a research community should benefit from and not be disadvantaged by, the research project; the negotiation of outcomes should include results specific to the needs of the researched community; and negotiation should result in a formal agreement for the conduct of a research project, based on good faith and free and informed consent.

Mechanics of grant rounds

AIATSIS maintains a research grants program to facilitate research by external researchers in the area of Aboriginal and Torres Strait Islander Studies. Applications are online at www.aiatsis.gov.au with comprehensive information available to guide the applicant to provide the information sought by the RAC and REC to assess applications on its merits.

All applications are independently assessed by staff of the Research Division, the RAC and Council and subsequently reviewed by the REC. The REC makes recommendations to Council on ethical compliance, and may also attach pre-conditions. In its final decision, Council considers all comments made separately by the RAC and the REC on the applications before an offer is made to fund a project.

Funds will be available from 1 July 2008. The total funds available for new grants in 2008 will be up to \$680 000. The total value of applications received each year greatly exceeds the funds available; around one third of applications are funded. Over the past three grant rounds, the average number of grants awarded per year was 33 and had an average value of \$20 794.

AIATSIS research grants

AIATSIS supports types of research that might include:

1. **Archaeology** (including material culture) concerned with research relating to any aspect of the archaeology of Australia, including Indigenous technology, economics, rock art, and traditional demographic patterns.
2. **Australian Indigenous art** that is created or made by Australian Indigenous peoples. It includes many forms of creative expression from conceptual, to performance, written, musical, or visual media. Indigenous art has been since time immemorial individual yet at the same time collaborative and event oriented. AIATSIS grant funding is directed to

research of Indigenous artistic activity. Funding for artistic production is supported by other agencies such as the Australia Council.

3. **Education and Cultural Transmission** concerned in the broadest sense, with all aspects of the organisation of teaching and learning, incorporating its processes and outcomes.
4. **Health and Biological Sciences** that supports studies of the social, cultural and environmental contexts of Indigenous health. Biological science research is concerned with the biological basis of the human organism, behaviour and demographic distribution in the present and past.
5. **History** that refers to past human activity in Australia. It relates to Indigenous oral histories, the interrelationship between Indigenous people and non-settlers such as Macassans, and to Indigenous relationships with settlers from the earliest arrival of European explorers up to the present.
6. **Linguistics** that includes descriptive studies of Indigenous languages, grammars, dictionaries and vocabularies (including pidgins/creoles and forms of English), collection and analysis of texts in Indigenous languages, comparative and historical studies of dialects or groups of languages, sociolinguistic studies, issues of language maintenance, education, and translation.
7. **Public Policy, Politics and Law** that includes discussion of government policy and law relating to Indigenous peoples in Australia; the engagement of Indigenous peoples with Australian law; and the recognition of Indigenous laws.
8. **Social Anthropology** that broadly refers to ethnographic studies of contemporary social and cultural life, particularly in relation to family life, economy, landholding and religion.

The AIATSIS Research Program does not fund:

1. Projects whose sole purpose is publication or production costs, purely archival or sourcing/collating of materials, returning materials to communities or repatriation of material, or research for native title claims. This includes: publication costs of books, videos, CD-ROMs and other media; production of media such as videos, CD-ROMs, paintings and artefacts (unless they are part of the documentation of research to be lodged at AIATSIS or with the community).
2. The salary of a researcher who is a university staff member. An exception may be made when the proposed research necessitates teaching relief or leave without pay.
3. Activities of organisations which are regularly funded by governments to carry out these activities as part of their normal responsibilities.
4. Conference attendance. However, small workshops or seminars or courses for the specific purpose of contributing to a research project may be funded.
5. Evaluations, descriptions or histories of institutions or programs carried out by the institutions/programs themselves or staff members. In order to be eligible for funding such projects should be carried out primarily by independent scholars.
6. Biomedical/clinical projects that do not include a significant Indigenous social or cultural research emphasis. These would normally be referred to the NHMRC for consideration.
7. Capital works or major asset purchases.

AIATSIS Research Advisory Committee

The Research Advisory Committee:

- assesses applications for research grants made to the Institute;
- makes recommendations to the Council in relation to research matters; and
- advises the Council in relation to applications for membership of the Institute.

The Research Advisory Committee of the Institute consists of:

- three members of the Council appointed by the Council;
- eight members of the Institute, elected by the members of the Institute in

- accordance with the Institute rules; and
- the Principal

The Committee usually meets *at least twice* a year.

AIATSIS Research Ethics Committee

The AIATSIS Council appoints a minimum of seven members to the Research Ethics Committee who must fill required categories: chairperson, layman, laywoman, person involved in caring professions, minister of religion or equivalent, person knowledgeable about research, and lawyer. AIATSIS Council required that at least one member be Indigenous and its practice is that the Chair should be Indigenous. The REC currently has two Indigenous members. Committee members attend in their personal capacities and not as representatives of community interest groups.

The REC operates under the *Commonwealth Authorities and Corporations Act* (CAAC Act) and the provisions of the Australian Public Service including the APS Code of Conduct. All the contents of protocols and of committee proceedings are confidential. Information will be made available only to those authorised to receive it, namely members of the RAC and Council.

The REC is concerned with the clearance of community based research to be carried out by its staff (including Research Fellows, Visiting Research Fellows and consultants) and grantees as well as external collaborative research projects to be carried out with AIATSIS staff under the auspices of AIATSIS.

The REC is responsible for reviewing only the ethical aspects of research projects, not the overall quality of research itself, which remains the responsibility of the AIATSIS RAC and Council.

The REC also ensures that grantees (internal and external) are informed through its *Guidelines* and feedback from its assessment of grants on the culturally appropriate methods of carrying out research in Aboriginal and Torres Strait Islander communities.

Assessment of grant applications

Research proposals are assessed against the following general criteria which are found online in the Information Guide for AIATSIS Research Grants (AIATSIS 2007). They are:

- The project is appropriate to the AIATSIS aim of identifying, promoting and conducting research in areas of relevance and priority to Australian Indigenous peoples, and contributing to scholarship in Aboriginal and Torres Strait Islander studies.
- The project will make a significant contribution to knowledge in Aboriginal and Torres Strait Islander studies.
- The applicant provides a satisfactory answer to the questions on the application form relating to Aboriginal and Torres Strait Islander community involvement with, and support for, the proposed project.
- The research project is of high quality and is clearly and competently described.
- The project is feasible given the applicant's skills and experience.
- The applicant has demonstrated the relationship between the proposed project and other work in the same field.

The RAC gives particular and positive emphasis to the following categories:

- Aboriginal and Torres Strait Islander people and organisations applying to carry out individual or collaborative research projects, including community history research projects.
- Emerging researchers and/or innovative research unlikely to be funded from other sources.
- Seeding funding for larger original projects.

- Research designed to capture information at risk of imminent loss.
- Relations with Government
- Knowledge About and Caring for Country
- Indigenous Knowledge Systems

Ethical considerations

The REC uses its own *Guidelines* as a tool to assess all applications in serious contention for funding. The REC is particularly looking for the following to be addressed by the researcher and where it is relevant to the project.

- **tangible outcomes** that might include reports or journal articles, conference presentations, video or sound recordings.
- **outcomes that are accessible** and/or useful to individuals or communities who have been subjects of the research.
- **community support for the project** developed in consultation with relevant Indigenous communities, and supported by them. This might include individuals, local community groups, or State or national umbrella groups.
- **benefits for the community/individual** where research is being conducted and reciprocal benefits should accrue for allowing intimate access to their personal and community knowledge.
- **collaboration with communities/individuals** is encouraged so that an Indigenous perspective can be incorporated in the research.
- **products that can be returned** to the communities or individuals that might include community report(s), publications, photographs, audiotapes, and DVDs that were collected and/or compiled during the research. The process of identifying who to make these items available to and also identifying what restrictions are placed on its access should be clearly thought through by the researcher.
- **products such as raw data, analytical information** that would be added to the AIATSIS collections and what form(s) these might take. This might need to be subject to any privacy, cultural or legislative requirements including any conditions set out in the “informed consent” documents.
- **informed consent** is an essential requirement for all research conducted with, for and / or on behalf of Indigenous people. It means that participants in the project understand what information is being collected, why it was collected and what it will be used for. If a grant is offered, researchers **MUST** provide written evidence of informed consent from individuals and groups involved in the project. Failure to supply adequate evidence of consent may result in any grant offer being revoked. Matters to be covered by an informed consent form include:
 - a 1-page Plain English statement about the project to be provided to the community/individuals before they have been consulted so that a negotiated agreement can be reached;
 - a pro forma (example or sample) of the informed consent form that will be provided to participants throughout the project which explicitly states the terms of ownership of intellectual property arising from the research (copyright, patents etc). A pro-forma informed consent form is on the AIATSIS website at www.aiatsis.gov.au/data/assets/pdf_file/8392/AIATSIS_HUMAN_RESEARCH_ETHICS_COMMITTEE-Infomed_Consent.pdf.
- **the Informed Consent Menu** is a table of options available to choose from according to the type of research that is proposed. The REC will have its own view of what is appropriate and steps should not be skipped. The purpose of this Menu, and the *Template for a Plain English Research Statement*, is to ensure that anyone who participates in the research project is *informed* about:
 - i. how the researchers propose to conduct the research,
 - ii. what the researchers are asking them to do,
 - iii. what the research products will be,

- iv. who will own them and rights to reproduce them,
 - v. how the researcher will protect personal or culturally restricted information,
 - vi. what will happen to any raw data (including whether it will be stored with AIATSIS)
 - vii. how the researcher will tell the participants the results, and that they consent to all of these things before participating in the research.
- **Institutional ethics clearance** is required if the researcher is attached to an organisation that has a human research ethics clearance procedure (e.g. most universities). AIATSIS **MUST** be provided with a copy of the institutional ethical clearance. If this document is not provided, or evidence that clearance is not required, the grant offer may be revoked.
 - **storage of material** with AIATSIS is encouraged for researchers to deposit their data and research products with AIATSIS where appropriate. Whenever possible, AIATSIS will suggest suitable locations for the conservation of collections which it is unable to hold.
 - **other participants** must be listed who will be working with the researchers on the project, or people who the researcher anticipates will need to be involved (such as interpreters, translators, field assistants, community participants with specialist knowledge).

Legal considerations

Privacy

The REC uses the *Guidelines* approved under Section 95 and 95A of the *Privacy Act 1988* as well as the Information Privacy Principles (IPPs), to assist the Committee in the assessment of research protocols dealing with personal information.

The REC needs to satisfy itself that those carrying out research involving the collections, storage, use and disclosure or other use of personal information are aware of and compliant with the *Guidelines* and the IPPs to ensure that the privacy of persons to whom personal information relates is protected.

The last few years has seen a major expansion in the volume, complexity and scale of legislation which regulates how organisations collect, store, manage, use and disclose personal information.

In an increasingly security conscious and technologically advanced society, individual privacy is increasingly important to people. People want personal information to remain private and want to ensure that only the right (authorised) people have access to it.

Privacy is a fundamental human right, but it's not an absolute right. In terms of information, personal privacy is the protection of personal information from unauthorised access and disclosure. There are laws and regulations which enforce the right to protection of personal information (but, of course, some laws override this right – e.g. laws concerning criminal investigations).

Privacy can mean different things to different people. There is no simple definition of privacy to cover all circumstances. 'Privacy' can mean the right to a sense of personal autonomy, the right to have information about oneself used fairly and also a right to be left alone.

An applicant for research funding must address in their application the protection of personal privacy and cultural information. How will the researcher protect the personal privacy of individuals/families? This is very important because it has implications for biographies, historical research, archival research or collection based research as well as field research. It is particularly relevant to digital recordings, photographs etc which can be easily disseminated to wider audiences. Consideration needs to be given to the potential impact of any research on culturally restricted information. The question of how materials will be stored, and access

moderated, both during and at the conclusion of the project needs to be very clearly addressed by the researcher.

It is also vitally important that researchers inform the people they are gathering information/stories from how personal information will be protected. People must consent to the methods of protection proposed by the researcher. The REC requires signed consent forms to evidence consent.

Intellectual property

This is an issue that is often not adequately addressed by researchers in their applications. Intellectual Property (IP) represents the property of the mind or intellect, for example things that Indigenous people have created or invented such as an original design or the practical application of an idea.

IP law can only protect a product or thing if it is in a physical or 'tangible' form. So for these laws to be able to protect Aboriginal people's rights in their culture, such as their dreaming stories, ceremonies, knowledge of country, including plants and animals, this knowledge has to be written down, filmed, or recorded in some way. Once this is done, the material is protected by copyright laws.

Copyright

Copyright is one form of IP rights, and it is often not adequately addressed by researchers. Copyright legislation protects the original expression of ideas, not the ideas themselves. If you have the copyright in something, you have the exclusive right to license others to copy the work, perform it in public, broadcast it, publish it or make an adaptation of it. Researchers need to consider who will own the copyright in, for example, a book they intend to publish containing the stories they have recorded.

Depending on the material, copyright generally lasts 70 years – either from the year of the author's death or from the year of first publication after the author's death. Copyright for films and sound recordings lasts 70 years from their publication. For broadcasts, it lasts 70 years from the year in which the broadcast was made.

Issues

Protocols

From the point of view of the REC, at least since 2005, it has been gratifying to know that some researchers are being educated about the most appropriate way to interact and conduct research studies with Aboriginal and Torres Strait Islander peoples. The aim of the REC is to continue to educate researchers and keep them well informed so that they understand and comply with the community's protocols and therefore their behaviour is conducive with the complexities of the research being undertaken.

Complaints

All complaints are dealt with, in the first instance, by the Director of Research, who will endeavour to resolve them in a timely and satisfactory manner. Should the complainant wish to take their complaint further, they will be advised to contact the AIATSIS Principal or the AIATSIS Chairperson.

The Director of Research will inform members of the AIATSIS REC of any complaint received that is relevant to the ethical aspects of the research and all steps taken to address such complaint. There is also an avenue for complaints to be lodged with the Chairperson of the REC regarding any of the projects.

Research Ethics Committee's feedback – both ways

To grant applicants

The REC ensures that grantees (internal and external) are informed through its *Guidelines* and feedback from its assessment of grants on the culturally appropriate methods of carrying out their research in Aboriginal and Torres Strait Islander communities.

Whether the feedback is to ask for more information, to clarify a point or to praise a good project, this is done through correspondence by AIATSIS Research staff on behalf of the REC.

From AIATSIS Council

The REC has received feedback from Council particularly when there have been quite different assessments of an application. The REC is only concerned about the ethical nature of the application. The feedback from Council is usually verbal and can be either through Research staff or with a meeting with the Council Chairperson.

References

AIATSIS 2002 *Guidelines for Ethical Research in Indigenous Studies*.

AIATSIS 2003 *Australian Institute of Aboriginal and Torres Strait Islander Studies Annual Report 2002–2003*.

AIATSIS 2007 *New Information Guide for AIATSIS Research Grants — Information Guide October 2007* <www.aiatsis.gov.au>

AIATSIS Research Ethics Committee Terms of Reference, May 2005.

AIATSIS Human Research Ethics Committee, Informed Consent, <www.aiatsis.gov.au/data/assets/pdf_file/8392/AIATSIS_HUMAN_RESEARCH_ETHICS_COMMITTEE-Informed_Consent.pdf>

Desert Knowledge Cooperative Research Centre, <www.desertknowledgecrc.com.au/socialscience/downloads/DKCRC-SS-BP1-Intellectual-property-rights-in-Australian-law.pdf>

Australian Government, IP Australia <www.ipaustralia.gov.au/ip/introduction.shtml> and <www.ipaustralia.gov.au/ip/copyright.shtml>

Commonwealth of Australia ‘What is Intellectual Property?’ <www.ipaustralia.gov.au/ip/index.shtml>