



WIPO/GRTKF/IC/16/INF/5(F)
ORIGINAL: ENGLISH
DATE : MAY 3, 2010

INTERGOVERNMENTAL COMMITTEE ON INTELLECTUAL PROPERTY AND GENETIC RESOURCES TRADITIONAL KNOWLEDGE AND FOLKLORE

Sixteenth Session
Geneva, May 3-7, 2010

WIPO INDIGENOUS PANEL ON FREE, PRIOR AND INFORMED CONSENT: EXPERIENCES IN THE FIELDS OF GENETIC RESOURCES, TRADITIONAL KNOWLEDGE AND TRADITIONAL CULTURAL EXPRESSIONS: EXPERIENCES FROM AUSTRALIA

Document prepared by

*Mr Russell Taylor
Principal
Australian Institute for Aboriginal and Torres Strait Islander Studies*

* This document comprises the presentation in the form received from the presenter. Any views expressed in the presentation are not necessarily those of WIPO or any of its Member States.

1. Introduction

I wish to discuss the issue of Free, Prior and Informed Consent (FPIC) in the context of supporting and promoting ethical research involving Indigenous Australians.

In this context I speak in a dual capacity as both an Indigenous Australian and as the Principal of the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), - an organization which has carried out, commissioned and supported research involving Indigenous Australian (Aboriginal and Torres Strait Islander peoples) for almost 50 years.

2. About AIATSIS

Originally established in 1961, AIATSIS is an Australian Commonwealth statutory authority established by the [*Australian Institute of Aboriginal and Torres Strait Islander Studies Act 1989*](#) (AIATSIS Act). AIATSIS operates within the agency portfolio responsibilities of the federal Minister for Industry, Innovation, Science and Research and is governed by a Council of nine members, eight of whom are Indigenous Australians.

AIATSIS's functions include:

- undertaking, promoting, and publishing Aboriginal and Torres Strait Islander studies;
- encouraging or conducting research in relevant fields;
- assisting to train researchers (particularly Aboriginal persons and Torres Strait Islanders);
- maintaining a cultural resource collection of materials relating to Aboriginal and Torres Strait Islander studies;
- encourage understanding, in the general community, of Aboriginal and Torres Strait Islander societies.

AIATSIS is an internationally unique organization and is the largest research centre of its kind for information about the cultures and lifestyles, traditional and contemporary, of Australian Indigenous (Aboriginal and Torres Strait Islander) peoples.

The corporate objectives of AIATSIS involve the following:

- funding, conducting, monitoring and assisting research;
- assisting to train researchers;
- developing, maintaining and cataloguing the archival and manuscript collections, and providing reference services to users;
- publishing and disseminating quality information on Aboriginal and Torres Strait Islander studies;

- increasing Aboriginal and Torres Strait Islander involvement at all levels, and promoting both equal employment opportunity and an affirmative action policy through effective training;
- producing reference aids (such as bibliographies) to facilitate public access to information and archival materials;
- providing expert advice and assistance on aspects of Aboriginal and Torres Strait Islander life and cultures on request;
- promoting public discussion of issues affecting the life and cultures of Aboriginal and Torres Strait Islander people and Aboriginal and Torres Strait Islander studies.

3. Principles Underpinning Research Involving Indigenous Peoples

As a basic tenet, approaches to research involving Indigenous people must be based on respect for Indigenous people's inherent right to self-determination, and our right to control and maintain our culture and heritage. Indeed, in my view, these principles are not only a matter of ethics, but are also fundamental to our human rights.

Ms. Erica-Irene Daes, Chairperson Rapporteur of the United Nations Working Group on Indigenous Populations, has remarked¹ that:

Heritage can never be alienated, surrendered or sold, except for conditional use.

Sharing therefore creates a relationship between the givers and receivers of knowledge.

The givers retain the authority to ensure that knowledge is used properly and the receivers continue to recognize and repay the gift.

Accordingly, in my view it is imperative that researchers adopt, as a non-negotiable operational ethos, approaches which demonstrate professional respect and commitment to ensuring that:

- Indigenous peoples are involved in and consulted as legitimate participants in any research project that concerns them;
- A shared understanding be achieved between the researchers and the Indigenous peoples about the aims and methods of the research;
- Indigenous peoples must be informed - in ways that are useful and accessible - and share in the results and flow-on outcomes of the research.

¹ Erica-Irene Daes, 'Discrimination against Indigenous peoples: Study on the protection of the cultural and intellectual property of Indigenous peoples', paper presented to the 45th session of the Commission on Human Rights, Economic and Social Council, United Nations, New York, 1993, p.9.

At every stage, including during the preliminary scoping and design of the methodology, research with and about Indigenous peoples must be founded on a process of meaningful engagement and reciprocity between the researchers and the Indigenous peoples concerned. This must be underpinned by the critically important notion that any Indigenous decision-making must be based on **free prior and informed consent**.

In my presentation today I want to talk about the ethics involved in conducting such research through specific reference to and focus on ethical research guidelines developed by my organization, AIATSIS over the past decade.

4. The Primacy of the local Indigenous perspectives

It needs to be said that effective analysis and understanding of the inter-cultural issues at stake in any research involving Indigenous peoples needs to be viewed from a 'local' perspective and on a specific project by project basis.

Any broad inter-cultural understandings, however well defined and understood, will nevertheless require testing, clarification, refining and checking as to their legitimacy and relevance at the local level.

In the Indigenous cultural context (certainly in Australia), this is of paramount importance and simply cannot be overlooked. Indigenous ways of learning, knowing, deciding and interacting in relation to the world at large vary greatly from community to community (and this means any practice manual or code of ethics must be flexible and not prescriptive in terms of local representative structures or protocols for the handling of knowledge and confidentiality – it must be organic by definition). Local Indigenous protocols will determine the relationship between the Indigenous stakeholders and the researchers - including who has the cultural and/or institutional legitimacy to speak on behalf of Indigenous stakeholders, clans, community and/or country. Fortunately, in the Australian context, there are various Indigenous organizations (e.g. Local Land Councils etc) that can legitimately represent and negotiate on behalf of local Indigenous interests.

Too many important research projects suffer or run the risk of failing their purpose because the local cultural aspects have not been adequately respected and taken into consideration.

In the Australian contexts, this is becoming critically important. From an inter-cultural perspective, the need for local Indigenous ownership and accountability of outcomes is of the utmost importance to Indigenous communities.

5. AIATSIS Guidelines for Ethical Research in Indigenous Studies

Consistent with the foregoing principles, owing to its history and the strengthening relationship and influence with the Australian Indigenous community, AIATSIS has developed an ethical research framework known as the *AIATSIS Guidelines for Ethical Research in Indigenous*

Studies (hereafter referred to as the AIATSIS Guidelines). It should be noted that AIATSIS provides grant funding support to the research community and in this context the AIATSIS Guidelines, overseen by an AIATSIS Ethics Committee and a Research Advisory Committee, provides the framework for grantee research methodologies and behaviour. It should be noted also that the AIATSIS Guidelines have been adopted by various Australian discipline based professional associations.

The AIATSIS Guidelines are articulated in Attachment 1 to this paper and grouped under 6 sub-headings:

- A. Rights, Respect and Recognition
- B. Negotiation, Consultation, Agreement and Mutual Understanding
- C. Participation, Collaboration and Partnership
- D. Benefits, Outcomes and Giving Back
- E. Managing Research: Use, Storage and Access
- F. Monitoring, Reporting, Review and Compliance

I would make the point that in developing these ethical research principles, AIATSIS is not attempting to establish any institutional cultural policing role, but rather to simply provide a practical framework aimed at achieving the best ethical and cultural standards for research occurring in inter-cultural contexts.

6. Free, Prior and Informed Consent (FPIC)

Importantly, all elements of the AIATSIS Guidelines are underpinned by the notion of **free, prior and informed consent (FPIC)**. However this paper has a focus on sub-heading B -Negotiation, Consultation, Agreement and Mutual Understanding.

AIATSIS Guidelines prescribe that researchers must understand the meanings of free, prior and informed consent. Additionally the steps that need to be taken to ensure that the processes required to bring about free, prior and informed consent also need to clearly understood and adopted by researchers.

From an AIATSIS Guidelines perspective:

- Free, prior and informed consent means that agreement must be obtained free of duress or pressure, and ensuring that Indigenous people are fully cognizant of the

details, and risks of the proposed research. Informed consent of the people as a group, as well as individuals within that group, is important.

- Free, prior and informed consent is defined in the following way:
 - ‘**Free**’ means that Indigenous peoples should give consent to research projects and the development and management of research outcomes and products freely, without coercion or interference by those seeking the consent.
 - ‘**Prior**’ means that researchers must ensure Indigenous peoples’ consent is freely given before any authorised commencement of a research project.
 - ‘**Informed**’ means that consent from Indigenous peoples must be obtained only on the basis of a full, accurate and adequately informed understanding and information provision to the Indigenous peoples concerned. Information about research projects must be made available to Indigenous people in ways that are understandable and accessible. Where possible, information about research projects should be made available in relevant languages, and by means of workshops, community meetings and discussions.
- The processes to achieve free, prior and informed consent consists of the following steps:
 - Information about a project is provided to Indigenous participants and all Indigenous people who will be affected or potentially affected by the project. This information should include the nature and purpose of the research, who is doing it, what will be the expected outcomes, what kind of information is being sought and how, and in what form, and how the research data will be managed. This should also include actual and potential implications for research products and outcomes, including possible publication, production of reports, registers and databases, and in what form (including new media, digital, and so on), and commercialization possibilities.
 - Indigenous people should be provided with this information in forms that are accessible, understandable, and, where appropriate, in community languages. Researchers should explain the project to Indigenous people in face-to-face situations, including at community meetings, and with the use of interpreters and translators.
 - Indigenous people should be given sufficient time to discuss the information in their own ways.

- It is important that Indigenous peoples understand that they can say 'no' to a project at any time, and 'revisit' the project, to renegotiate and/or question and amend any aspect of the project.
- It is important that Indigenous people are made aware that free, prior informed consent is a process and is ongoing throughout a project.

7. FPIC Consultative Processes

Consultation, negotiation and free, prior and informed consent are the foundations for research with or about Indigenous peoples.

Researchers must ensure that Indigenous people are full participants in the research process. This also recognises the obligation on researchers to give something back to the community.

It is ethical practice in any research on Indigenous issues to include consultation with those who may be directly affected by the research or research outcomes whether or not the research involves fieldwork.

Research with Indigenous peoples should be carried out with appropriate negotiation and consultation about the aims and objectives and meaningful negotiation of processes, outcomes and involvement. Relevant communities and individuals should be involved at all stages of the research process, from formulating projects and methods to determining research outcomes and interpreting results.

To facilitate appropriate consultation, negotiation and free, prior and informed consent, the following process is encouraged:

- Identify appropriate individuals and communities who should be consulted about the research project. There is almost always someone to speak for a particular place or area. For more general research it is important to, identify and consult individuals or communities who have made an important contribution in relation to the topic.
- Allow appropriate individuals for the area/topic to be identified from within the community.
- Ensure that the Traditional Owners who speak for the country concerned are involved.
- Identify Indigenous regional, local and community and/or other representative organizations.
- Identify any written research protocols or other protocols that you will need to follow.

- Observe appropriate community values, norms and protocols.
- Identify potential political issues that may be affected by your research or the outcomes of the research.
- Communicate with relevant individuals and organizations by appropriate means. Face-to-face meetings are always desirable. The budgetary and funding implications of such visits should be considered.
- Introductions to the relevant individuals and communities should clearly identify the researchers and any other participants, any institutional affiliation and key stakeholders, and sources of financial support.
- From the outset, objectives should be clear, while maintaining flexibility and a willingness to modify your goals and ways of working.

8. FPIC Mutual Understanding

Consultation and negotiation should achieve mutual understanding between the researchers and the Indigenous peoples involved in the proposed research.

Consultation involves an honest exchange of information about aims, methods, and potential outcomes (for all parties). Consultation should not be considered as merely an opportunity for researchers to tell the community what they, the researchers, may want.

Being properly and fully informed about the aims and methods of a research project, its implications and potential outcomes, allows Indigenous people to decide for themselves whether to oppose or to embrace the project.

Obtaining agreement to conduct research with or about Indigenous peoples involves fully informing the community, Traditional Owners and others about the proposal, discussing the research and negotiating how the research is to proceed.

- Identify the appropriate Indigenous communities and individuals to be consulted before discussing research aims, methods and outcomes.
- Clearly define and explain the purpose and nature of the study, who is carrying it out and funding it, what are the objectives of the research, and what are the likely impacts and consequences of the study, including production of research outputs, publication and commercialization.
- Explain methods of collecting information clearly and comprehensively, including how and where the information is to be kept.
- Agree on the way of conducting the research, including timing and phasing of the project.

- In order for research to be conducted appropriately and sensitively, discuss relevant cultural and political circumstances.
- Be clear about what kind of community or individual participation is sought.
- Clearly identify what participation in the study may entail for the community and individual participants.
- Provide an honest assessment of the risks or potential adverse impacts of the research.
- Provide any environmental and social/cultural impact assessment studies and their outcomes as they impact on the research.
- Provide to research participants examples of other research being done by the person(s)/group(s) seeking access, and how well the project(s) went and any problems that were encountered and how those were addressed.
- Explain, but do not overstate, the potential benefits of the study.
- Explain the potential usefulness of the research to Indigenous peoples in general.

Remember:

- Provide sufficient time for discussion and consideration of proposals.
- Be willing to modify the scope, aims and methods of the proposed research.
- Allow time in the research project for continual review, feedback and discussion.

9. FPIC and Effective Negotiation

Negotiation should result in a formal agreement for the conduct of a research project, based on good faith and free, prior and informed consent.

The aim of the negotiation process is to come to a clear understanding, which results in a formal agreement (preferably written), about research intentions, methods and potential results.

The establishment of agreements and protocols between Indigenous peoples and researchers is an important development in Indigenous studies.

- Where practical, a written agreement (a 'protocol', or 'memorandum of understanding' or 'contract') should be the end result of the consultation and negotiation, to protect the community and the researcher and to clarify the understandings that have been reached. Such agreements may have legal implications and consideration should be given to whether independent legal advice is required.

- Base the agreement on good faith negotiations and free, prior and informed consent.
- Identify who should enter into the agreement, and on whose behalf the agreement is being made.
- In negotiating and developing good, equitable research agreements, it is important to:
 - Consider any permits or permissions that may be required from Indigenous organizations and from governments and/or local authorities.
 - Consult ethical guidelines or codes of ethics of the appropriate professional body or association, and
 - Determine what information is to be included in the agreement, based on discussions and negotiations. The agreement should reflect the mutually agreed aims, processes and outcomes, community participation and collaboration.
- The agreement should provide a detailed and clear description of the ownership and licensing of intellectual property rights. Rights to record and/or film require clearance from participating interviewees/subjects
- A research agreement should, where possible, take into account the research needs of the local Indigenous people, and the appropriate Traditional Owners.
- Recognise in the agreement that an individual or a community has the right to withdraw from a research project.
- Include in the agreement processes for resolving conflict, such as mediation by an outside party.
- Refer to any specific Indigenous community protocols in the agreement, and ensure that these are respected and upheld.
- For successful implementation of the agreement, continue consultation and negotiation and, where necessary, re-formulate the agreement.

10. FPIC consultation and negotiation is ongoing

Consultation and negotiation is a continuous two-way process. Ongoing consultation is necessary to ensure free, prior and informed consent for the proposed research, and of maintaining that consent.

Research projects should be staged to allow continuing opportunities for consideration of the research by the community. This can be achieved through regular formal feedback sessions.

Community representatives, individual participants including Traditional Owners, and the wider Indigenous community may need time to consider a proposed research project and to discuss its implications, both before it begins and at various stages of the project.

- Ensure that all potentially interested individuals are present at preliminary meetings and/or are informed of the scope of the proposed research.
- Obtain (do not assume) invitations to visit the community for the time necessary to conduct the research and to report upon results.
- Explain research methods and processes to individuals and at community meetings where appropriate, and reach agreement on their cultural appropriateness.
- Reach agreement on how the research should proceed, including processes and timing for informing representatives of the community of the progress of the research and reporting any interim results.
- Ensure that Indigenous people have the right to decline, or withdraw their involvement in a research project at any stage.
- Phase your research according to community as well as research needs.
- Be willing to renegotiate objectives, where required, in light of new factors and considerations.
- If necessary, re-formulate a new outline of the research proposal, and provide new materials generated from the discussions to the community for review.
- Report during the project in accordance with any agreement.
- If necessary, consult further about any unforeseen matters that might affect the research process.
- Make provision for a final meeting to consider the results of the research. Further consultation may also be required about details of reports and any publications.

11. Conclusion

Research does not occur in a cultural or ethical vacuum.

This paper has attempted to offer some principles and guidelines for ethical, inter-cultural research and research practices involving Indigenous peoples by reference to the work of the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and its ethical guidelines.

As a basic tenet, approaches to any research involving Indigenous peoples must be based on respect for Indigenous people's inherent right to self-determination, and our right to control and maintain our culture and heritage. Mutually respectful, inclusive, consultative research practices in the before, during and after stages are seen as the preferred model of practice.

Research with and about Indigenous peoples must be founded on a process of meaningful engagement and reciprocity between the researchers and the Indigenous peoples concerned and be underpinned by Indigenous decision-making based on free, prior and informed consent.

[End of document]