

[Section 6]

RESEARCH INVOLVING ABORIGINAL PEOPLES

During the drafting of this Policy Statement, suggestions were made to create a section dealing with research involving Aboriginal Peoples. The Agencies, however, have not held sufficient discussions with representatives of the affected peoples or groups, or with the various organizations or researchers involved. The Agencies have therefore decided that it is not yet appropriate to establish policies in this area. The text of Section 6, which builds on the extensive literature on research involving Aboriginal Peoples, is intended to serve as a starting point for such discussions.

A. Introduction

There is growing recognition that some research involving Aboriginal individuals may also involve the communities or groups to which they belong. The Agencies affirm that in developing ethical standards and practices, Aboriginal Peoples have rights and interests that deserve recognition and respect by the research community. This section thus has three aims: to assist researchers and REBs in determining which projects might involve research on such groups; to illustrate ethical issues and conduct for such research; and to indicate good practices that researchers should consider.

Guidance on these issues comes from at least two sources. The first is the ethical principles, standards and procedures articulated throughout this Policy. Thus, for example, ethics review should be proportionate to the risks of potential harm. As well, informed consent and the concepts of harm, benefits and confidentiality should be informed by the perspective of the participant group.¹ For the expertise essential to effective ethics review, REBs may need to involve academic or community members from representative groups, or advisory committees drawn from relevant communities (see Article 3.4(c)). Such approaches and the principles are consistent with the work of SSHRC some two decades ago.²

The second source of ethical guidance comes from the specific additional provisions developed in Canada and in other countries for research involving Aboriginal Peoples. Beginning in Australia in 1986, research agencies and Aboriginal Peoples have set out guidelines for the conduct of research in Aboriginal communities. These guidelines do not replace ethical standards for the conduct of research on individuals; they seek to suggest additional requirements to ensure that the rights and interests of the community as a whole are respected. International,³ Australian,⁴ Canadian (see below) and American⁵ guidelines are currently available. The high degree of agreement and consensus among these guidelines is remarkable, perhaps reflecting commonalities in the experience of these communities and the sharing of existing guidelines among communities.

Three documents are especially relevant to research on Aboriginal Peoples in Canada. They were prepared by the Association of Canadian Universities for Northern Studies,⁶ the Royal Commission on Aboriginal Peoples⁷ and the Inuit Circumpolar Conference. Researchers and REBs considering research involving Aboriginal communities should be familiar with the relevant documents. All three documents agree on the following requirements for research involving Aboriginal communities.

Research may involve Aboriginal communities when it focuses on the community, its subgroups or individuals as members. The research may seek information on the characteristic beliefs, values, social structures or other features by which members identify themselves as group members. Alternatively, the group may be involved in the conduct, direction, sponsorship or implementation of the research. A general principle is that the obligation to respect human dignity in research involving Aboriginal groups gives rise to both special considerations and to basic ethical duties regarding ethics review, informed consent, confidentiality, conflict of interest and inclusion (see Sections 1-5). This principle is not intended to preclude critical inquiry and research, or research that may come to negative conclusions; rather, it seeks to advance accurate, informed and ethical research.

In Canada and elsewhere, Aboriginal Peoples have distinctive perspectives and understandings embodied in their cultures and histories. This Policy Statement recognizes the international consensus that has developed over recent decades that Aboriginal Peoples have a unique interest in ensuring accurate and informed research concerning their heritage, customs and community.

Research involving Aboriginal communities may raise difficult ethical issues, sometimes novel and sometimes old. As indicated in the Ethics Framework described in this Policy, for example, research that is premised on respect for human dignity entails high obligations to individuals and groups. Indeed, there are historical reasons why Indigenous or Aboriginal Peoples may legitimately feel apprehensive about the activities of researchers. In many cases, research has been conducted in respectful ways and has contributed to the well-being of Aboriginal communities. In others, Aboriginal Peoples have not been treated with a high degree of respect by researchers. Inaccurate or insensitive research has caused stigmatization. On occasion, the cultural property and human remains of Indigenous Peoples have been expropriated by researchers for permanent exhibition or storage in institutes, or offered for sale. Researchers have sometimes treated groups merely as sources of data, and have occasionally endangered dissident Indigenous Peoples by unwittingly acting as information-gatherers for repressive regimes. Such conduct has harmed the participant communities and spoiled future research opportunities.

Other aspects of research involving Aboriginal Peoples present ethical challenges. Since researchers may belong to a different culture, for example, debates may arise because of different definitions of public and private life. Notions of property will sometimes differ between the researcher, sponsors and the community. Language differences may impede clear communication and understanding that is instrumental to the informed consent process. A researcher may also be confronted by ethical dilemmas because of competing interests among different sections of the community.

For reasons such as these, when research involves Aboriginal individuals, researchers and REBs should consider the interests of the Aboriginal group, when any of the following considerations applies:

- (a) Property or private information belonging to the group as a whole is studied or used;
- (b) Leaders of the group are involved in the identification of potential participants;

- (c) The research is designed to analyze or describe characteristics of the group; or
- (d) Individuals are selected to speak on behalf of, or otherwise represent, the group.

The considerations above outline the proposed situations in which REBs should review the need for involving the community in research involving Aboriginal Peoples. Item (a) includes cultural properties⁸ as understood by the Aboriginal community in question and may include human tissue (Section 10). Item (b) covers research where the group is asked to assist in recruiting its members, or to give official approval and permit access to their property. Together, items (c) and (d) would include research in which members are interviewed as spokespersons for the group as a whole. The central issue for discussion is when it is legitimate for researchers to interview individuals in their own right as individuals, without regard to the interests of the group as a whole and without seeking permission from any group authority or spokesperson or, conversely, when the approval of the community as a whole should be required.

B. Good Practices

Researchers and REBs involved with Aboriginal communities should consider the following “good practices,” which have been drawn from the documents referred to above:⁹

- To respect the culture, traditions and knowledge of the Aboriginal group;
- To conceptualize and conduct research with Aboriginal group as a partnership;
- To consult members of the group who have relevant expertise;
- To involve the group in the design of the project;
- To examine how the research may be shaped to address the needs and concerns of the group;
- To make best efforts to ensure that the emphasis of the research, and the ways chosen to conduct it, respect the many viewpoints of different segments of the group in question;
- To provide the group with information respecting the following:
 - Protection of the Aboriginal group’s cultural estate and other property;
 - The availability of a preliminary report for comment;
 - The potential employment by researchers of members of the community appropriate and without prejudice;
 - Researchers’ willingness to cooperate with community institutions;
 - Researchers’ willingness to deposit data, working papers and related materials in an agreed-upon repository.
- To acknowledge in the publication of the research results the various viewpoints of the community on the topics researched; and

- To afford the community an opportunity to react and respond to the research findings before the completion of the final report, in the final report or even in all relevant publications (see Section 2 on information disclosure).

Aboriginal Peoples may wish to react to research findings. It is inappropriate for researchers to dismiss matters of disagreement with the group without giving such matters due consideration. If disagreement persists, researchers should afford the group an opportunity to make its views known, or they should accurately report any disagreement about the interpretation of the data in their reports or publications.

End notes

- ¹ Medical Research Council of Canada, *Guidelines on Research Involving Human Subjects*. Ottawa, 1987, pp 27–28.
- ² Social Sciences and Humanities Research Council of Canada, *Ethics Guidelines for Research with Human Subjects*. Ottawa, 1977, p.1-2 (affirming, as regards collective rights, the right to be fully informed about the nature and purpose of the research to enable the informed choice of the group; the right to assurance that privacy will not be invaded and that any information disclosed will remain confidential; the right of living members of a society regarding the entry of “outsiders” to examine their burial grounds or cultural property, or to exhibit and dispose of these objects).
- ³ Inuit Circumpolar Conference, *Principles and Elements for a Comprehensive Arctic Policy*. Alaska, Greenland, Canada, 1992; Council for International Organizations of Medical Sciences, *International Guidelines for Ethical Review of Epidemiological Studies*. Geneva, 1991.
- ⁴ National Health and Medical Research Council of Australia, *Guidelines of Ethical Matters in Aboriginal and Torres Strait Islander Health Research*. Canberra, 1991.
- ⁵ American Anthropological Association, *Statement on Ethics: Principles of Professional Responsibility*, Adopted by the Council of the American Anthropological Association, May 1971; American Public Health Association Task Force, *National Arctic Health Science Policy*. Washington, D.C., 1984; American Indian Law Center, *Model Tribal Research Code*. Albuquerque, 1994; and U.S. Interagency Arctic Research Policy Committee, “Principles for the Conduct of Research in the Arctic,” *Arctic Research of the United States*. Spring 1995, 9: 56–57.
- ⁶ Association of Canadian Universities for Northern Studies, *Ethical Principles for the Conduct of Research in the North*. Ottawa, 1982, reprinted 1988.
- ⁷ Royal Commission on Aboriginal Peoples, Appendix B: *Ethical Guidelines for Research*. Ottawa, 1993.
- ⁸ See, e.g., UNESCO, *Convention on the Means of Prohibiting and Preventing the Illicit Import, Export and Transfer of Ownership of Cultural Property*. Paris, 1970.
- ⁹ See, e.g., American Anthropological Association, *Statement on Ethics*. 1991; American Indian Law Center, Inc., *Model Tribal Research Code*. 1994, 2nd ed.; Board of the Swiss Academy of Humanities and Social Sciences and of the Swiss-Liechtenstein Foundation for Archaeological Research Abroad, *Principles for Partnership in Cross-Cultural Human Sciences Research with a Particular View to Archaeology*. 1994;. Canadian Archaeological Association, *Statement of Principles for Ethical Conduct Pertaining to Aboriginal Peoples*. 1996; Association of Canadian Universities of Northern Studies, *Ethical Principles for the Conduct of Research in the North*. 1997.