Ethics for Research with Indigenous Peoples

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Understanding the term “indigenous”

Considering the diversity of indigenous peoples, an official definition of “indigenous” has not been adopted by any UN-system body. Instead the system has developed a modern understanding of this term based on the following:

- Self-identification as indigenous peoples at the individual level and accepted by the community as their member.
- Historical continuity with pre-colonial and/or pre-settler societies
- Strong link to territories and surrounding natural resources
- Distinct social, economic or political systems
- Distinct language, culture and beliefs
- Form non-dominant groups of society
- Resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities.
A question of identity

• According to the UN the most fruitful approach is to identify, rather than define indigenous peoples. This is based on the fundamental criterion of self-identification as underlined in a number of human rights documents.
A guide for academic and community partners to work together: useful in developing regions

CINE/WHO 2003

http://www.mcgill.ca/cine/resources/
Why Does Research with Indigenous Peoples (IP) Need Special Consideration?

- In developing countries, IP often have little voice in health structures. May lack services and experience discrimination
- Need for mutual understanding when communications are lacking (i.e. language barriers)
- Problems may be culturally and politically specific
- Benefits of research rarely accrue to IP
Participatory Methods

• Discussions and support from Aboriginal organizations (Collective consent)

• Consultation on research process and funding

• Research agreements with each community, with detail on responsibilities of local leaders and researchers (Community consent)

• Community members employed in research data and sample collection

• Informed consent of individual participants (Individual consent)

• Discussion of progress and results with communities before publication and media
THE DOCUMENT IS A FIRST STEP:

1. A template of basic research principles focused on Indigenous Peoples
2. A focus on joint management of health research

THE DOCUMENT PURPOSELY IS NOT:

1. A guide to intellectual property rights
2. A substitute or replacement for national or international research ethics procedures
3. A culturally specific ethics guideline
CIHR Guidelines for Health Research Involving Aboriginal Peoples

- September 2005, draft completion; revised April 2006; now approved by CIHR
- Rigorous and sensitive issues addressed by a strong committee
- Excellent outline of the research approval process recommended
- 15 articles that include
  - Community jurisdiction over conduct of research
  - Intellectual property rights
  - Community control over use of data
  - Etc.
Rules tightened for aboriginal studies

Canada's main funding agency for health research has adopted ethics guidelines for studies involving the estimated one million indigenous people in the country.

Researchers and tribal leaders are optimistic that the guidelines will help to speed up the investigation of health problems among Canadian aboriginals, whose life expectancy has been estimated to be between five and eight years shorter than that of other Canadians. This is due in part to a greater susceptibility to diabetes, cardiovascular disease and mental-health problems.

The guidelines — the first to offer a comprehensive framework for researchers working with aboriginal communities — state that scientists should focus on the collective interests of the community in planning their studies. For example, they must obtain consent for projects from the community involved, as well as from individuals. Biological samples should be considered "on loan" to the researcher, and the community should have the opportunity to review the conclusions drawn from the data.

"This is a big step forward," says Alan Bernstein, president of the Canadian Institutes of Health Research (CIHR), the main federal funding agency for health research and the author of the guidelines.

Until now, Canadian researchers working with indigenous people have relied on the guidance in a 1998 human research ethics statement issued by the Tri-Council (see Nature 395, 420; 1998), a body comprising three federal research agencies, of which the CIHR is one. Ethicists have argued that its comments on indigenous peoples are inadequate, and agencies have long recognized the need to beef up the guidance.

"Standards were quite uneven across the country," says Jeff Reading, scientific director of the Institute of Aboriginal Peoples' Health (IAPH), which is part of the CIHR.

The guidelines were prepared by the Ethics Office of the CIHR and the IAPH, in partnership with the aboriginal communities of First Nations, Inuit and Metis. A working group surveyed the research guidelines developed in other countries and by aboriginal groups to explore the issues raised by research involving aboriginal people.

Although the recommendations are not legally binding, health researchers and institutions funded by the CIHR will be required to follow them.

The relationship between researchers and aboriginal communities has been problematic in the past. So-called fly-in researchers would come into communities, take samples, and never be seen again. The issue was thrust into the public eye in 2000, when the Nuu-chah-nulth, a First Nations community living on Vancouver Island, British Columbia, discovered that DNA samples collected between 1982 and 1983 to study the high incidence of rheumatic disease in the community had been later used in other research projects, including an anthropological study that was not part of the original consent (R. H. Ward et al. Proc. Natl Acad. Sci. USA 88, 8720–8724; 1991).

Global genetics projects such as the Human Genome Diversity Project and the Genographic Project, which both explore human origins and migrations, have also met with opposition from aboriginal groups, partly because there were no obvious benefits to the community.

Hannah Hoag
1: Understand cultural responsibilities that accompany traditional knowledge or sacred knowledge and strictly comply with community expectations and protocols

2: Community jurisdiction over the conduct of research must be understood and respected

3: Communities should be given the option of a participatory research approach

4: Obtain free, prior and informed consent from individual participants and the Aboriginal community as appropriate

5: Respect and address confidentiality concerns of the community and individuals

6: Include of cultural knowledge in research under mutually agreed terms with the guidance
FOCUS Article 4: A process for free, prior and informed consent at individual and collective levels

Consent processes must take into account Aboriginal community’s own decision-making processes, in all phases of planning, implementation, monitoring, assessment, evaluation and closure of a research project.

This requirement of collective community consent is distinct from the obligation of researchers to obtain individual consent from each research participant.
7: Protect cultural knowledge shared with the researchers. Aboriginal peoples and their communities retain inherent rights to their knowledge, cultural practices and traditions.

8: Indigenous concerns over and claims to intellectual property must be explicitly acknowledged and addressed as part of the research process and outlined in a research agreement.

9: Research should be of mutual benefit to the community and researchers.

10: Researchers should support the development of education, research, and training (including training in research ethics) for Aboriginal peoples and communities.
11: Researchers have an obligation to learn about and apply Aboriginal cultural protocols relevant to the particular Aboriginal community

11.1 Ideally translate all related publications or reports into the language of the community

11.2 Ensure effective on-going communication in a manner that is accessible and understandable to the community
12: Aboriginal communities have inherent rights to control and determine their proprietary interests in the collection, use, storage and potential future use of data.
13: Biological research samples should be considered “on loan” to the researcher.
14: All Aboriginal communities should have an opportunity to participate in the interpretation of data and/or review of conclusions drawn from the research to ensure accuracy and sensitivity of interpretation.
15: It is the discretion of the community partners as to how their contributions will be acknowledged. Community members have the right to due credit and participation in dissemination of results and publications must recognize the contribution of the community where appropriate and in keeping with confidentiality agreements.