

CIHR Revisions to Ethics Guidelines for Research with Aboriginal Populations

January and February 2006 Workshops in Nova Scotia and New Brunswick

Summary Report

This report is based on two workshops that were held in January and February 2006. The purpose of the workshops was to inform Aboriginal community-based personnel, researchers, university-based academics, and government representatives about the latest version of the Canadian Institutes of Health Research (CIHR) Ethical Guidelines for Health Research Involving Aboriginal People (September 2005 version) and receive feedback from them on what improvements needed to be made to the latest draft of the guidelines. This report will serve as an addendum to the larger report prepared by the Atlantic Aboriginal Health Research Program (AAHRP) in August 2005.

Thirty-four participants attended the two meetings in Moncton, NB and Truro, NS. Ms. Doris Cook of the CIHR presented information about the guidelines at both meetings and Ms. Barb MacGillivray, former past President of the NCEHR, and currently with the University of British Columbia, provided information about research protocols at the first meeting.

This report provides general comments about the guidelines and specific comments about either articles or the information contained in the ethics document. The two workshops were relaxed and informal, and participants were encouraged to interject as needed. Overall, while participants commented that the information presented was informative and that the guidelines were an important step to helping improve the way that health research is conducted in Aboriginal communities, many had recommendations about how to improve the guidelines. The following highlights the concerns and/or recommendations made by participants of these two meetings.

Discussion/Concerns:

The notion that the guidelines are really intended to serve the Aboriginal community was challenged, and it was stated that the guidelines may better serve the Aboriginal community if they speak more to Aboriginal people, are user-friendly, and provide more advice about what Aboriginal people should ask of the researcher.

If the guidelines were meant to support mutually-beneficial research, then there should be a recommendation that no research be conducted until the community has a working set of ethics guidelines in place. Without such guidelines, researchers are able to take advantage of the Aboriginal community, using loopholes to conduct their research - research that may not be beneficial to the Aboriginal community.

Concern was expressed that the guidelines do not address the issue of the need for financial resources to be made available to Aboriginal communities so that they are able to take part in the dissemination of research results. Without these resources, the researcher is seen as the expert, rather than the community, as Aboriginal community members are not often able to take part in the dissemination activities (e.g. due to financial constraints, they are unable to attend a conference to share findings). Related to funding is the reality that some communities do not know what they are getting into with respect to research, but it is essential that they get involved in research, as research results are often a requirement by government funding agencies in order for the community to receive funds they need for programs and services.

One participant said that the information outlined under Article 12 contradicts the principles of OCAP, in that it says that the community (partner) should get approval from the researcher (other partner) for secondary use of the data for their own purposes. Following the OCAP principles, the data would belong to the community rather than the researcher, so this issue should be clarified.

The need for academics to have cultural competency, whereby professors would be taught the cultural realities of Aboriginal students, so that the student's work is better understood, should be clearly addressed in the guidelines. A participant cited an example where cultural competency would have been useful to a professor who had marked a paper low because the professor was not aware that Aboriginal oral tradition was a valid methodology. This is addressed, somewhat, in the guidelines in that the intent of the guidelines is to direct researchers on cultural competency. However, universities need to take the initiative to learn about Aboriginal culture, and their commitment to learning will affect their level of cultural competency. It is also the university's responsibility to inform its faculty about the guidelines. It was noted that handbooks on the guidelines are being developed for both universities and communities, and should be ready by the time the guidelines are adopted. One participant made the point that when the tri-council speaks, universities listen, and if there is a general education component to the guidelines, universities will learn about them beyond just the converted. The guidelines need to be shared broadly.

One participant said that the guidelines provide no protection for copyright. The research becomes the intellectual property of the researcher, and it no longer belongs to the Aboriginal community. This is unacceptable. The guidelines need to state that the information gathered is the community's information, and that the researcher should only be permitted to share what the community has approved or what has been agreed to in the research agreement. Another participant said that when the guidelines point out that communities have the right to retain their own intellectual property such as in Article 8, the realities of this statement are misleading and untrue. CIHR needs to say that it supports the rights of the community to retain their own intellectual property, even though the legal advice it's received says that it cannot make such statements. This article is also rather short and needs to be expanded to provide more information.

Participants agreed that the guidelines should not refer to concepts as if all Aboriginal people follow them. For example, the term ‘sacred space’ is not a concept used by Aboriginal people in the Atlantic Provinces. The use of words and concepts to describe a common spirituality should be avoided, as Aboriginal spirituality varies across the country. It was also noted emphatically, that no one representing Atlantic Aboriginals was on the advisory committee tasked to draft these guidelines, and as a result, concepts of importance to Aboriginal people in the Atlantic Provinces are not included in these guidelines. More needs to be done to make these guidelines more inclusive of Aboriginal people throughout Canada.

Regarding the analysis of research, one participant said that the understandings or findings may be misleading if the cultural context is not included. Without the specific cultural realities, a truthful analysis of the situation cannot be done. As well, unless the Aboriginal community is included in the research in a participatory way, the real issues will not be identified. In article 14, the reference to the right of Aboriginal communities to participate in the interpretation of data was challenged in that the article does nothing to safeguard against the sole interpretation of the data by the researcher. The mechanism through which the interpretation of the results is done needs to be accessible to the Aboriginal community (e.g. community sessions, community reports). Another level of protection could involve including a statement in the guidelines which says that findings do not have much validity until they have had some interpretation from the involved Aboriginal community.

Researchers, it was noted, sometimes come to Aboriginal communities with the idea that they know what’s best for the communities. One participant said that to counter this, their community established a health board that is knowledgeable enough about research to hold such researchers at bay. This participant wanted to know how to inform researchers about these guidelines, because they are not opposed to research, but just want the researchers to be informed. CIHR will be holding education sessions across the country informing academic institutions about the guidelines. Information will be provided about when the educational sessions are scheduled for Atlantic Canada.

Lastly, concern that researchers could begin to ‘shop around’ for communities that are not knowledgeable about their rights in the research process was raised with agreement that this would be less likely to occur once the guidelines have been broadly shared.

Recommendations:

To reiterate, participants said that they felt that the guidelines were a good starting point to helping improve how research is done in Aboriginal communities and that these guidelines need to be shared broadly to have impact. They did, however, have recommendations to improve the guidelines and following is a summary of their input.

When the issue of unethical behavior of a researcher, in general, was discussed, a participant said that rather than follow bureaucratic procedures to rectify the situation,

that a website be created that allows on-line complaints about researchers that the public can access. This website could also contain information such as the OCAP Principles which could inform anyone who visited the site. Another participant recommended that consumer reports showing which institutes are not rigorous in following ethics protocols be developed, and that such reports be available to Aboriginal communities. This could be available on a website as well.

It was recommended that “gray” areas in the guidelines be improved. For example, who do researchers consult in urban areas? These guidelines need to provide enough information so that researchers know where to go for advice and approval to conduct research with Aboriginal people, and that they know what protocols should be followed when doing such research.

It was recommended that words such as “should” be replaced with words such as “must” in the guidelines, so that there is no ambiguity. Participants were informed that CIHR had received a legal opinion recommending that it not use certain words, but this information did not dissuade participants from agreeing that stronger words are needed in the guidelines as a means to better protect Aboriginal people from unethical researchers.

Another participant recommended that included in the research agreement should be the ability of the Aboriginal participants to have in the finished product, a clause stating that the Aboriginal participants did not agree with the interpretation of the results. With participatory research, this sort of disagreement is less likely to occur, but if a disclaimer is to be added to the final product, the ability to do so must be laid out in the research agreement. The inclusion of such a disclaimer may dissuade researchers from interpreting the results without the help of Aboriginal people.

One participant expressed concern with the ethics review process when attempting to identify appropriate community involvement. It was recommended that a letter of support from the Aboriginal community be included, or that a research agreement between the Aboriginal participants and the researcher be used as a means to show appropriate community involvement.

Besides the need for academics to learn about the guidelines, there is a responsibility for those who develop policies, such as those in various governments, to learn about the guidelines as well. Policy makers should know what is required of researchers when doing research with Aboriginal people, so that when they develop policies that impact Aboriginal people, the data they use or gather upon which the policies are based, is appropriate and ethical, and therefore likely to have more of an impact on Aboriginal people.

A student recommended that other students need to become aware of diversity issues outside the mainstream ones, and that a course on cultural diversity should be a mandatory course for students. At the very least, students doing research with Aboriginal people should be required to learn about and understand these guidelines.

With respect to Article 11, it was recommended that a statement be included to say that researchers enter into the research process with Aboriginal people as ‘learners’, as it was noted that researchers learn a lot from their work with Aboriginal people. Researchers are gathering information in conjunction with Aboriginal people for better understanding. It was emphasized that expertise lies with both the researcher and the Aboriginal partners.

Finally, another participant recommended that a protocol and research committee, with experienced Aboriginal community members, be established which could provide advice to researchers who want to work with Aboriginal communities. The Mi’kmaq Health Research Group in Nova Scotia functions in a similar way, and other such groups could be established in other provinces. Such a committee could also watch for breaches that have been made to the research protocol or agreement.

Summary:

Following consultations with Aboriginal communities, the guidelines document will be revised using information gathered during these input sessions. When the revisions are completed in mid-March, the document will be sent to the Standing Committee on Ethics and then to the Governing Council to be adopted. The guidelines are meant to be used by research ethics boards, researchers, students, and communities and they are meant to function as the minimal acceptable standards for research with Aboriginal communities. These guidelines are not meant to supersede local ethics guidelines, and the guidelines providing the most protection for Aboriginal people should be used.

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