

CIHR Ethical Guidelines for Health Research Involving Aboriginal People Atlantic Aboriginal Health Research Program (AAHRP) Summary Report of Community Sessions

Introduction:

This report is in response to a call from the Institute of Aboriginal Peoples' Health that the ACADRE Centres contribute to the development of ethical guidelines for Aboriginal health research, and more specifically, to contribute to the development of Section 6 (Research Involving Aboriginal Peoples) of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, which in its current form, has been recognized to be inadequate when conducting research with Aboriginal people.

Consultations with invited participants, both Aboriginal and non-Aboriginal community-based personnel and university-based academics, were carried out in May and June 2005 throughout the Atlantic region, with two sessions held in Nova Scotia, two in New Brunswick, which included participants of Prince Edward Island, one in Conne River, Newfoundland and one in Happy-Valley/Goose Bay, Labrador. Participants were provided with the draft document in advance of the sessions. The community sessions were organized around a Power Point presentation of the draft guidelines, followed by an open discussion from participants, facilitated by staff or board members of AAHRP.

The overall view of participants was that while the draft guidelines provided by the CIHR Ethics Office were far better than the previous guidelines and that they show willingness on the part of CIHR to facilitate better relationships between Aboriginal communities and researchers, this current draft still requires more work. The following is a summary of the discussions and recommendations provided by participants of our regional community sessions.

Points of Discussion and Recommendations:

1. To begin, a few participants expressed concern about the motives of CIHR in developing these new guidelines. It was argued that CIHR is an arm of the federal government and that at least part of its mandate is the commercialization of knowledge gained from research. The proposed guidelines, then, were seen as part of a top-down agenda to make it easier for researchers to access indigenous knowledge and thereby deprive Aboriginal people of one of their few remaining assets. In keeping with this agenda, it was felt that there is a bias to the guidelines, that they imply a right to have research done and knowledge shared. Furthermore, it is assumed that the researcher is always from outside the community.

Some felt that the guidelines should be thrown out and a more grass-roots process to build an alternative code should begin with appropriate financial support. The vision of research that was put forward was one where Aboriginal people control research funds

and are in the ‘driver’s seat’ around how and by whom research is conducted. The concept of ownership of knowledge should be defined from an Indigenous perspective, and any benefits from the commercialization of knowledge should accrue to the Aboriginal people involved. There was particular concern expressed about medical research and the suggestion was made that there should be a moratorium on such research, as well as a position of non-compliance, until new structures and funding mechanisms are in place.

While not everyone took this position, it did reflect an unhappiness with how research has been carried out in the past and the lack of structures and processes whereby Aboriginal people could influence and shape research in a more positive direction. While some felt that the draft guidelines should be thrown out, others took the view that they were certainly an improvement over what had existed in the past.

2. A common theme that emerged throughout the sessions was the feeling that the guidelines were written in a high level language by academics, for academics, resulting in guidelines that were not reader-friendly for community-based researchers and others in the community. It must be remembered that one of the purposes in developing these guidelines is to involve Aboriginal communities in the research and ethics review process. Participants agreed that the language needed to be changed and that this could be done by having a combination of academic and layman terminology in the guidelines. Furthermore, the language should be accessible and concise so that it is translatable.

Participants also felt that the document was very lengthy and that it should be shortened. If it is not possible to shorten the document, then a summary should be prepared and made available for use by Aboriginal communities. The summary could include the articles with bullets that explain each article in point form.

3. Participants felt that the introduction was long and disheartening. Researchers need to be encouraged to develop partnerships with Aboriginal people that are respectful, but not in a way that could be interpreted negatively. Some participants felt that the present document, in particular the introduction, might frighten off some good researchers. Some also expressed concerns that the accountability to seven generations referred to in the document could make university researchers more skittish about doing research with Aboriginal communities.

Others, however, felt that these guidelines were no more onerous than ethical guidelines found at universities, school boards and hospitals, so should not discourage potential researchers.

4. Provision of a standard research agreement template, written in language that is easy to understand, could be provided for use by both the Aboriginal and academic communities. The agreement should include wording that states that should an Aboriginal community decide that specific information proposed to be gathered should not be released, this request will be adhered to by the researcher. In addition, if the Aboriginal community is not in agreement with the analysis of the research, then they

need to be given real opportunities to make their views known regarding the analysis, particularly before the final report is drafted.

5. Another overriding theme that emerged was the belief that more must be done at the university level to change its research environment so that it is more supportive of research with Aboriginal people. For example, the tenure process for academics does not favour taking an extended time to conduct research, which could be the case when doing research with Aboriginal communities. Aboriginal community protocols for the release of research data are sometimes not adhered to when researchers are strongly encouraged to use the data for tenure/promotion purposes (e.g. asked to present data at a conference before its release has been approved by the community).

Universities also need to recognize the efforts of the researcher, even when the Aboriginal community decides that it is not in the best interest of their community to release the information gathered in the study.

Participants said it is essential that both the will of the university community and the research framework they follow change if meaningful research is to be conducted in Aboriginal communities. Academic researchers and Aboriginal community collaborators need to be in an equal partnership so that research is conducted in a respectful manner where the potential for harm to the community is reduced. As long as this relationship is good, there is more likelihood that the research will be done well and will benefit the community. Also, if time and effort have been spent on building that relationship, then the horror stories of past research in Aboriginal communities are less likely to be repeated.

To help prevent some of the frustrations of both the Aboriginal community and university-based researcher in the research process, more information needs to be included in the guidelines that inform researchers about the realities of conducting research in Aboriginal communities. This information could be provided in the introduction and it could also outline the types of research this would generally involve.

Attention also needs to be given to educating members of research ethics boards or administrators of ethics protocols in universities about the guidelines if they are going to be applying these guidelines.

6. It was recommended that researchers interested in conducting research with Aboriginal people needed to be culturally competent, rather than just be culturally aware or culturally sensitive. Cultural competency refers to the need on the part of the researcher to respect, understand, and acknowledge the beliefs, values and lived realities of the Aboriginal community and its members¹. Cultural awareness/sensitivity on the part of the researcher is not good enough when conducting research with Aboriginal communities, as it only scratches the surface when entering into a relationship with

¹ Adapted from "Providing Health Care, Achieving Health", Mary Jane Hampton & Abby Hampton, September 2005.

Aboriginal communities. While researchers may exhibit knowledge of Aboriginal culture, they more importantly need to be the right fit in the research relationship with the community. Flexibility is a key to this relationship.

7. Participants recommended that these draft guidelines be fluid and changeable, so that they would accurately reflect the ever changing needs of Aboriginal people. Aboriginal elders, youth, off-reserve individuals, and others in the community must be given opportunities to provide input, through further consultations, and to transform the guidelines as needed. Participants recommended that the guidelines be reviewed every four years.

8. It was recommended that traditional knowledge (TK) be protected and honored and that efforts by researchers be made to understand this knowledge in consultation with the community. Mechanisms to protect TK must be included in research agreements so that it is not exploited.

9. In all locations, there was considerable debate over the issue of who decides on behalf of the community to give consent for a research project to proceed. In particular, there were differing views over whether the elected political leadership has the right to veto research when it places the leadership in a conflict of interest situation. The most common view was that not all research should need the approval of Chief and Council, particularly when the Council is clearly in a conflict of interest situation, such as would be the case for example in a study that looks at the community effects of video lottery machines that provide revenue for the community.

The contrary view was also forcefully expressed, however. It was argued that the political leadership is elected by the community and it is the ultimate arbiter of what research should proceed. If they make mistakes, then the community has the option of electing a new leadership at the next opportunity.

No one had any confidence in the suggestion contained in the draft guidelines that a dispute over a research project should be referred to an impartial appeal body at a higher level. In the first place, such appeal bodies do not exist in most areas. Secondly, participants did not see how a regional appeals board would have any authority to overrule individual community leadership and autonomy, so did not feel that this idea would work. It would create an untenable situation for a researcher to come back to a community to undertake research that may have been supported by a regional appeal body but that does not have the support of the elected leadership of the community. They felt that it would be more effective for communities to put in place their own research appeals boards that had the authority to overrule the leadership.

Related to this is the view that Aboriginal leadership should be given real opportunities to learn about the benefits of research and about concepts in research. If leaders are informed from the beginning about the proposed research and the potential benefits of the research for the community, then they are more likely to support the research. They should also be fully briefed on the ethics guidelines. Another interesting suggestion was

that the researcher and his/her community partners should build community support for the research in the first instance and then proceed for approval by the leadership. If the latter has objections, its concerns should be taken into account if possible and the research proposal revised in order to find common ground.

10. Participants felt that the information in the guidelines was open to interpretation and needed to be direct and concise. That is, too much onus is placed on the researcher to do what they say they will do, and not enough information is provided about what penalties would be placed on researchers who do not adhere to the ethical guidelines. Participants were interested in knowing how CIHR would hold researchers accountable to these guidelines? How would a community make a formal complaint against a researcher? If a community pulls out of a research project, who do they inform about this decision? If a community pulls out of a project, will CIHR stop funding the project? These are questions that require clarification.

11. There was a general view that the charts outlined in Section IV were confusing and incomplete. The charts must also reflect the need for Aboriginal communities to be full partners in the research process. This means they need to be present when the research question is being formulated. CIHR should allocate resources for partnership development. These resources should be made available to Aboriginal communities as well as to universities. It is not good enough to talk about partnership development in the guidelines without resources to support this partnership development.

The charts also need to reflect the dissemination of research results. Too often, the researchers feel the project is complete once they have reported the results back to the academic community. The charts need to clearly indicate the equally important need to report results back to the Aboriginal community.

12. Participants had much to say about accountability. There was general agreement that “accountability” involves “responsibility” and that Aboriginal people have their own ideas of what kinds of accountability are appropriate. However, not everyone was clear about what a sacred sense of accountability meant. Some preferred to describe the relationship in the first instance as a legal one embodied in a nation-to-nation treaty relationship. If research was organized on this basis, Aboriginal people would have the resources and control mechanisms to conduct and manage their own research. They would be in the driver’s seat.

Participants felt that if trust was first established, then accountability would take care of itself. They said that accountability goes both ways, where both the researcher and the research partners are accountable to each other, and therefore, need to be open to one another about what they want from each other.

Practically speaking, participants said that funding agencies need to be made explicitly aware that tight time lines do not work in Aboriginal communities. These time issues make accountability difficult for both the researcher and participant.

13. It was clearly stated that the principles of OCAP (ownership, control, access, possession) should be used to guide all research.

14. Participants expressed their concern that representation from the Atlantic Provinces was not included in the development of the draft guidelines. It has to be remembered that different cultures have different points of view and our participants would have had more confidence in the guidelines had an Aboriginal person from this area been involved in their development. The diversity, as well as the homogeneity of Aboriginal people must be considered.

15. Lastly, it was recommended that these guidelines be translated in the languages of the Aboriginal people who will be involved in the research process.

Discussion of Articles:

Article 1: Researcher must respect Indigenous world views

This article was not discussed in any detail.

Article 2: Community consent and jurisdiction over the conduct of research

One university-based participant took exception to the idea that these guidelines would attempt to address conflicts internal to a community. This individual said that research would not be approved by an ethics board without evidence of community support.

Some also expressed concern with the idea that community ethics codes and procedures should prevail in the event of conflict with university-based procedures. The concern was that community-based processes are not well developed in some communities and may well be inadequate. Communities may not be in a position to protect their interests. Thus, it would be better for the parties to work it out if there are conflicts.

Some participants also felt that political leadership should be the last to approve the research process and that approval should first be sought from the community, followed by Chief and Council. A change in political leadership can result in approval being revoked, and it was suggested that the political leadership would not disagree with the approval of the community, and in particular, with that of the elders. One individual said that in the Mi'kmaq culture, approval is first sought from the general public, followed by the political authority. Not all Aboriginal communities follow the same approval protocols and this must be noted in the guidelines.

Finally, participants expressed concern regarding community-based ethics review boards, in that they felt that these could be overruled by band councils and that this issue needed to be resolved. It was expressed that the band council is being given too much authority

over research in this document and that advocacy groups should be given opportunities to do the research they feel is important, despite the objections of the band leadership.

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

One participant took the position that it is not possible under current circumstances to develop true partnerships (implying a relationship among equals) when it comes to university-based research in Aboriginal communities. There is too much of an imbalance of power, with the university researcher getting the grant, administering the funds, implementing the research and then getting tenure on the basis of the results. A partnership cannot exist under conditions of inequality and duress. A related issue has to do with the inappropriateness of mainstream methodologies when applied in Aboriginal communities, which undermines the validity of the research that is conducted.

However, others provided examples of research in which they were engaged which they believed did represent valuable forms of partnership that yielded benefits both for the community and the researcher.

Article 4: Free, prior and informed consent from the community and individual

It was suggested that rather than use the term “free” when speaking of consent, that the word “voluntary” be used. Again, there was some questioning of the words and assumptions of this section, and the sentiment was expressed that it did not adequately describe a mutually respectful relationship. Who is the judge of whether informed consent is properly implemented? What are the sanctions for non-compliance? It was noted that all the recommended steps could be followed and you could still end up with a perverse result from the point of view of the Aboriginal community. At the root is the need to rebalance the power relationship and put in place appropriate research structures.

Participants also suggested that in order to be fully informed, some research participants would require an interpreter, versed in their own language and culture, as there could be cases where potential participants agree to take part in the research only because they were too embarrassed to admit that they did not understand what was being told to them.

Article 5: Confidentiality concerns of the community and individual participants must be respected and addressed

Participants agreed that the researcher has an obligation to make clear what amount of anonymity and confidentiality they can ensure and to remind the participant that they are not able to ensure that others, such as other participants in group sessions, would in all cases, keep information confidential. Researchers should also disclose to their community partner their obligation to report to external authorities, such as funding agencies. Agreements pertaining to confidentiality should be negotiated following federal/provincial laws prior to commencement of the research.

Article 6: Researchers should recognize that the principle of individual autonomy may be limited by the interests of the Aboriginal community as a whole

This article was not discussed in any detail.

Article 7: Research must be conducted with the guidance of Aboriginal people

While this article was not discussed in any great detail, it was clear from the discussions that this particular idea is a given.

Article 8: Aboriginal peoples and their communities retain rights to their knowledge, practices and traditions that are shared with the researcher

While not much was said about this article, it was noted that Aboriginal people can protect their traditional knowledge by agreeing to keep it within the community.

Article 9: Research must mutually benefit the community and researchers

Participants felt that a clear distinction needs to be made as to whether the research benefits the community or Aboriginal people in general. Overall, participants felt that this article was acceptable.

Article 10: Researchers should support capacity building

Participants were offended by the use of the word “empowerment” in the title before Article 10 which speaks to the issue of capacity building. They felt that the word implied that the researcher has power and that they can ‘give’ some of that power to the Aboriginal community, suggesting a one-way relationship. This article needs to reflect the reciprocity inherent in the relationship between the Aboriginal community and researcher. An alternative to the word “empowerment” was “knowledge-sharing”, and that the two way exchange of knowledge was a key to capacity building. Related to this was the suggestion that those providing the data/information should be acknowledged in any write up, and that all translators should be noted as well.

Article 11: Researchers should learn cultural protocol, translate related publications, and ensure effective communication

Participants felt that Article 11.1 should be re-worded to say that “Where appropriate, reasonable translations for all related publications or reports should be done in the language of the community”. What is appropriate and reasonable should be negotiated with the community at the beginning of the project. More importantly, a clear plan and budget for information to be disseminated to community members in a language they understand is needed.

Article 12: Aboriginal communities have rights to control and determine their proprietary interests regarding data

In Article 12, participants were unclear about what was being referred to as data. They felt that there was a need to recognize surveys, questionnaires, etc. as data. In some cases, this raw data may need to be in the possession of both the community and the researcher. In other cases, ownership may lie exclusively with the community. It should not be assumed that all CIHR funds will be exclusively awarded to a university-based researcher. Hopefully, CIHR is open to the possibility of awarding resources to communities to conduct research. They may then contract appropriate researchers. This might mean that the community retains both possession and ownership of the raw data. In this case, the community should be able to determine secondary use of the data without permission from the researcher.

Participants wanted clarification about who owns individual medical and school records that are used for research. Is this raw data owned or possessed by the institution? Does the information derived from that raw data belong to the community, the researcher or the institution? Possession and ownership should not be confused.

Article 13: Biological research samples should be considered licensed to the researcher

Participants said that the use of the word “need” must be replaced with the word “must” in the discussion of this article. Clarification prior to research commencement needs to take place as to who is responsible for destroying biological samples. For example, the research agreement should outline what will happen to the samples after they are taken, guarantees made by the researcher that the samples will be destroyed, and a date indicating when those samples would be destroyed.

Participants also recommended a wording change in the discussion following this article. Rather than state that “requests to withdraw, return or dispose of samples must be accommodated”, better wording would include “requests to withdraw, return or dispose of samples must be negotiated to the mutual benefit and satisfaction of both parties”.

Article 14: Aboriginal communities have the right to participate in the interpretation of data and review conclusions

Participants recommended that as another form of protection to the information they share, a disclaimer be provided in the final report, as per a research agreement, that the community does not agree with the interpretation of the conclusions, if that is the case. Participants felt that community members could have a different interpretation of the data and that they “must” be consulted prior to the research being published. This will ensure that the community’s point of view will be considered in the interpretation of the data. They also felt that with a good understanding of the Aboriginal culture, such as that of the Mi’kmaq, and including the perspective of that culture, interpretation of the

information will be more accurate. Ideally, the researcher should be fluent in the language of the particular group, so that words, concepts and ideas are adequately interpreted.

Also, they felt that community members must be careful about their interpretation and release of the data, as the final report would be available for the public to read.

Lastly, participants felt that a clear distinction between quantitative and qualitative research must be provided to research participants. Concern was raised that although the numbers in quantitative research are not disputed, it's the interpretation of those numbers that they dispute, particularly when those numbers are interpreted by non-Aboriginal researchers.

Article 15: Community members have the right to due credit and participation in the dissemination of results

This article was not discussed in any detail.

Conclusion:

Involvement of Aboriginal people in the development of the tri-council guidelines, including elders, youth, off-reserve individuals and others, cannot be underestimated. Their participation and input will help ensure that the information included in the guidelines will not only inform researchers about the realities of doing research in Aboriginal communities, but it will also help to protect the knowledge shared by Aboriginal people. Most participants in our sessions felt that the draft guidelines were a good starting point, as they will help strengthen Aboriginal peoples' ability to control research, keeping in mind that the development of the guidelines should not be rushed. Careful thought and consideration by all is needed to develop guidelines that will help reduce the incidence of unpleasant research experienced by Aboriginal communities in the past, and to support a positive experience for both the Aboriginal community and researcher today and in the future. Furthermore, participants felt that these guidelines should not be finalized until they have been revised and returned for further discussion and that a meeting of Aboriginal people be convened, without the research community present, so that a more free and comfortable discussion of the issues could take place. Lastly, universities need to be made aware of the guidelines through an organized communication strategy by CIHR.

Aboriginal communities must now begin the process of developing their own ethics guidelines for research, and these draft guidelines could provide a good starting point to begin this process. Concern, however, was expressed that given that these guidelines are complicated and that many Aboriginal communities do not have any ethics guidelines in place, they should be provided with adequate funding/resources to help facilitate this learning and development phase. For those communities that already have ethics guidelines in place, their own guidelines must be respected and applied. Eventually, the

hope is that ethics reviews by Aboriginal communities will be integral to any research process involving them. Efforts should be made by those involved in any ethics review process involving Aboriginal people to include someone who is fluent in the language of that Aboriginal community.

Practical recommendations for improvement of the guidelines included:

- changing the wording in the document to make the guidelines more reader friendly
- providing a clear and positive representation of the realities of conducting research with Aboriginal people
- ensuring that the guidelines have broad community input so that they better meet the needs of Aboriginal people and allow the guidelines to be fluid with a review conducted every four years
- providing options to leadership approval for research so that research that would not likely be approved could be conducted in the community or collective
- include a discussion that Aboriginal groups can form a collective that is not only defined by geography
- clarifying wording in the document, particularly when it comes to the roles and responsibilities of the researcher and Aboriginal community and recourse for both when situations change or research protocols are not adhered to
- clarifying the charts in Section IV
- replacing the words “ought” and “should” with the word “must” where appropriate.
- including examples of ‘best practice’ research agreements and case studies on research with Aboriginal people in the appendices

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