

Negotiating Ethical Agreements

FACT SHEET

In community-based research (CBR) an essential research skill is Negotiating Ethical Agreements to conduct research with Aboriginal communities and peoples. In all research it is essential to operate a project in an ethical manner that uses established guidelines for conducting research with human participants (refer to Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, specifically Section 6: Research Involving Aboriginal Peoples). Research ethics are generally defined as procedures designed to ensure that the welfare of the participants is placed above the needs of the research investigator. Research funded by any of the Federal Government Research agencies, such as the Canadian Institutes of Health Research (CIHR), requires that a research proposal explains how ethical guidelines will be strictly followed. Before a research project can begin, an 'ethics certificate' must be issued by a Research Ethics Board (REB). Research Ethics Boards are found in academic institutions and some Aboriginal communities and organizations have also developed Boards (e.g. Mi'kmaw Ethics Watch based in Nova Scotia, etc.).

In 2004, the Canadian Institutes of Health Research (CIHR) initiated a project to develop Aboriginal specific health research guidelines to ensure adequate protections for Aboriginal research participants. The health research guidelines are intended to contribute to the separate but related process of revising the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS). A working group has been established, national consultations have taken place based upon the draft document "CIHR Guidelines for Health Research on Aboriginal Peoples (2005) and it is hoped that the document will be finalized in 2006. These guidelines formally describe research ethics for working with the Aboriginal community. The ethics are based on building collaborative relations, creating awareness, using relevant methods and involving Aboriginal expertise. Collaborative relations refer to the meaningful involvement of community members in the research process. Creating awareness is necessary to show respect to Aboriginal peoples and to keep the community informed about the research steps and processes. The use of Aboriginal expertise supports direct local participation, has a vital role in the empowerment of community members and enhances the quality of the research overall. Culturally relevant research methods are essential for ensuring that in-depth data are gathered and interpreted in a manner that is sensitive to the issues affecting the community.

Aboriginal ethics guidelines uniquely address "the ethical principle of researchers respecting Indigenous world views, particularly when engaging the sphere of traditional knowledge

and the corresponding responsibility that possession of such knowledge entails." (CIHR, 2005, p13) When working with the Aboriginal community the context of the research is influenced by complex issues such as the balance between individual autonomy and collective communal interests when seeking consent. The development of Research Ethics Guidelines for and by Aboriginal peoples is a significant step towards implementing the principles of OCAP. Respecting that Aboriginal peoples have the right to maintain Ownership, Control, Access and Possession of the research process reflects the increased capacity within the Aboriginal community to conduct and recognize the benefits of research.

A Research Ethics Agreement or Memorandum of Understanding (MOU) can be negotiated to outline a clear set of ethical guidelines for a research study in a community or with a community organization. CAAN has developed the Principles of Research Collaboration (refer to Appendix) and made a presentation about this in an Abstract entitled 'One Example of Negotiating a Research Partnership' (Jackson et al. 2003) delivered during the 2003 Canadian Association for AIDS Research Conference. The Principles "acknowledge the importance of Aboriginal self-determination and establish the importance of research that moves beyond academic interest to research that is meaningful to the Aboriginal community." (Jackson et al., 2003)

Both CAAN and the working group revising the Guidelines for research with Aboriginal Peoples suggest that a protocol should include;

- Context about the research project to be collaborated on collective decision making agreements regarding determining research questions, participant recruitment and data collection;
- Consent processes and confidentiality;
- Data analysis and interpretation;
- Reporting and dissemination with an emphasis on knowledge translation back to the community where the research took place;
- Intellectual property rights and proper referencing;
- Management of funding; and
- Research project timeline and budget.



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As a key national voice of a collection of individuals, organizations and provincial/territorial associations, CAAN provides leadership, support and advocacy for Aboriginal people living with and affected by HIV/AIDS. CAAN faces the challenges created by HIV/AIDS in a spirit of wholeness and healing that promotes empowerment, inclusion, and honours the cultural traditions, uniqueness and diversity of all First Nations, Inuit and Métis people regardless of where they reside.

MISSION STATEMENT

- Established in 1997
- Represents over 200 member organizations and individuals
- Governed by a National thirteen member Board of Directors
- A four member Executive Board of Directors
- Provides a National forum for members to express needs and concerns
- Ensures access to HIV/AIDS-related services through advocacy
- Provides relevant, accurate and up-to-date HIV/AIDS information

OVERVIEW

The Canadian Aboriginal AIDS Network is a national, not-for-profit organization:

Bibliography

A number of sources were consulted in preparing these Principles of Research Collaboration. The Canadian Aboriginal AIDS Network acknowledges the contributions of the following sources:

Canadian Aboriginal AIDS Network (2002). Ownership, Control, Access and Possession Fact Sheet. Ottawa, Ontario.

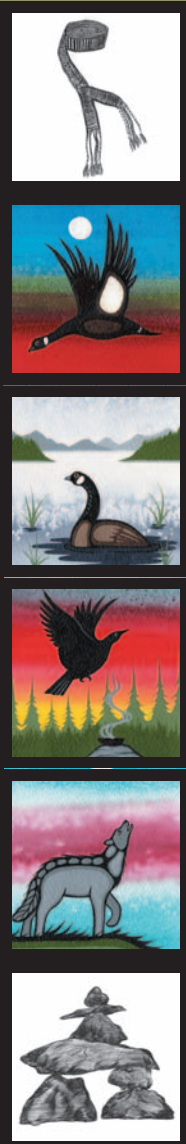
Huth, Edward (1985). "Guidelines on Authorship of Medical Papers." American College of Physicians. Annals of Medicine, 104: 269-274.

Israel, Barbara, Amy Schutz, Edith Parker and Adam Becker (1998). "Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health." American Review of Public Health, Vol. 19: 173-202.

Kaufert, Joseph, Laura Commanda, Brenda Elias, Roda Grey, Barney Masuzumi, and Kue Young (2000). "Community Participation in Health Research Ethics." Pushing the Margins: Native and Northern Studies. Eds. Jill Oaks, Rick Riewe, Maylyn Bennett, Brenda Chisholm. Native Studies Press, University of Manitoba: 50-51.

Kaufert, Joseph, Laura Commanda, Brenda Elias, Roda Grey, T. Kue Young, and Barney Masuzumi (1999). "Evolving Participation of Aboriginal Communities in Health Research Ethics Review: The Impact of the Inuvik Workshop." International Journal of Circumpolar Health, Vol. 58 (No. 2): 134-44.

Schnarch, Brian (2002). Ownership, Control, and Access. Ottawa, Ontario: National Aboriginal Health Organization. (Unpublished Presentation).



A final challenge regarding ethical review relates to access to a Review Board. Most often REB is based within an academic institution or hospital. Community-based researchers may find it difficult, if not impossible, to attain an ethics certificate without partnering with an institutional representative who can apply for a certificate from their institution's REB. Access to funding will require 'ethics approval' from a recognized REB and perhaps also from a local Aboriginal Research Ethics Board as well.

CAAN advocates that research institutions must include APHAs as members of Research Committees that deal with HIV/AIDS related research. Recruitment of HIV/AIDS research subjects may be difficult without the approval of Aboriginal communities or Aboriginal HIV/AIDS organizations for research to proceed. Issues such as the duration of the research (particularly when some participants may be ill), the use of appropriate, non judgemental approaches and the language in written material (culturally appropriate and sensitive terminology), best methods of recruitment, possible duplication of other research and the value of such research to the Aboriginal HIV/AIDS community will need to be discussed.

Conclusion

Strong ethical standards are outlined for research with Aboriginal Peoples to protect individual participants and community rights. Community-based research initiatives must meet these ethical guidelines to ensure research participants are not harmed by any aspect of the research process. An effective community-based research project brings together a variety of people on the research team, negotiating an agreement with partners that sets out ethical guidelines at the start of a project will assist with team building and clearly identify expectations.

Notes:

A number of sources were consulted in preparing this Fact Sheet. The Canadian Aboriginal AIDS Network (CAAN) acknowledges the contribution of the following sources:

Castellano M.B. Ethics of Aboriginal Research. Journal of Aboriginal Health, Vol. 1 (1), 98-114, 2004.

Canadian Institutes of Health Research Ethics Office. CIHR Guidelines for Health Research Involving Aboriginal Peoples Draft for consultation, version 1.8. Retrieved March 8, 2006, from <http://www.cihr-irsc.gc.ca/e/29339.html>. 2005.

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Retrieved from <http://www.pre.ethics.gc.ca/english/policystatement/policystatement.cfm>. 1998 (with 2000, 2002 and 2005 amendments).

Jackson R., Dixon L., Thomas K., and Zoccolle A. One Example of Negotiating a Research Partnership: Aboriginal community-based HIV/AIDS research principals in practice. Canadian Aboriginal AIDS Network CAAN, Ottawa, Ontario. Abstract presented at the 2003 Canadian Conference on HIV/AIDS Research CAHR. The Canadian Journal of Infectious Diseases, Volume 14 Supplement A, 2003.

Smylie J. and Colleagues. Health Sciences Research and Aboriginal Communities: Pathway or Pitfall? J. Obstet. Gynaecol. Can. 26(3), 211-216, 2004.

The Ethics of Research Involving Indigenous Peoples. Indigenous Peoples' Health Research Centre report to

the Interagency Advisory Panel on Research Ethics (CIHR, SSHRC, NSERC). Indigenous Peoples' Health Research Centre, Saskatchewan, 2004.

Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research. National Health and Medical Research Council NHMRC, Commonwealth of Australia, 2003.

Principles of Research Collaboration Between The Canadian Aboriginal AIDS Network And [INSERT NAMES]

Parties

This document constitutes Principles for Research Collaboration (PRC) between [INSERT NAMES] (investigators) and the Canadian Aboriginal AIDS Network, a national non-governmental organization dedicated to providing, support and advocacy for Aboriginal People living with and affected by HIV/AIDS regardless of where they reside.

The Canadian Aboriginal AIDS Network will participate as a member of the research team under the terms identified below through [INSERT NAMES].

The above listed individuals constitute the research team. Additional members may join in signing this PRC and participate as members of the research team once all members (listed above) have agreed.

Purpose

The purpose of this PRC is to establish a set of principles that guide the conduct of the research projects, "[INSERT PROJECT TITLE]" In short, this agreement acknowledges the importance of incorporating cultural values and perspectives into the research process.

Records

The Principal Investigator (PI or project coordinator will coordinate all administrative matters relating to the above named research project. The PI or project coordinator will provide each member of the research team with notes of meetings, including decisions made, within a reasonable time frame.

Ethical Considerations

Ethical codes of conduct for research in Aboriginal communities have been articulated in the Tri-Council Policy Statement. However, each member of the research team collectively shares the responsibility for raising ethical concerns and issues. Ethical dilemmas are resolved on the basis of the research team striving for a significant degree of consensus.

Duration and Amendments

This PRC will be in effect throughout the entire research process, from the development of research questions through data collection and analysis phases into dissemination of findings. This PRC can be amended upon mutual consent by members of the research team.

Principles: Ownership, Control, Access and Possession

The research team acknowledges and supports the principles of ownership, control, access and possession as outlined below:

- Members of the research team acknowledge and respect the Aboriginal right to self-determination, including the jurisdiction to decide about research in their communities. In doing so, the research process shall be build upon meaningful engagement and reciprocity between the research team and Aboriginal communities. Further, the research team agrees they will strive to respect the privacy, dignity, culture and rights of Aboriginal peoples.
- The research team will strive to include meaningful and equal participation from Aboriginal community members. Therefore, the parties agree they will be jointly and equally involved from beginning to end in the research process, from research question formulation, though data collection, analysis and into dissemination of research findings related to the above named project.
- The research team may also strive to demonstrate this support by obtaining and attaching letters of support from Aboriginal community leadership at the local level who may assist as either a member of a research advisory committee or in providing assistance related to the recruitment of participants. Primarily, the task of negotiating letters of support from local Aboriginal communities resides with the Canadian Aboriginal AIDS Network.
- The research team agrees that they will collectively make decisions on research questions, in data collection, interpreting results, in drafting research reports and in dissemination of findings. In other words, the PI will not present a completed research design for approval but involve all other members of the research team in the process.

- The research questions must not only reflect academic interests but strive to ensure that the research is also relevant and beneficial to Aboriginal communities.
- In dissemination strategies to Aboriginal communities, the research team agrees that the language and manner of sharing research will be appropriate.
- The (purpose of) research project will be explained to all stakeholders (participants and Aboriginal community members) in a language that is appropriate to the Aboriginal community. Likewise, the research team will explain potential risks and benefits in a similar manner.
- The research team agrees they will not sensationalize problems in Aboriginal communities. Rather, they will strive to present a balanced portrait that also focuses equal attention on more positive aspects. As such, the research team understands that they will collaboratively prepare draft findings prior to submission for publication or presentation. The parties agree to review findings in a timely manner (e.g. two months).
- Given that all members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation, any one member of the research team may not, particularly once initial dissemination has occurred, further analyze, publish or present findings resulting from the above mentioned research project unless the entire research team reaches a consensus.
- The PI is responsible for maintaining the integrity of all data collected, such as storing participant consent forms, etc. However, once privacy and confidentiality of participants has been demonstrated, data sets in the form of SPSS or QSR*N6 (NUD*IST) computer files may be shared with all members of the research team. In cases of disagreement over transfer of data sets (as described above), the research team will strive to achieve a significant degree of consensus.
- The research team agrees to provide meaningful and appropriate research capacity-building, as indicated by Aboriginal community participants.
- The research team agrees that Aboriginal communities have the right to follow cultural codes of conduct and community protocols. However, rather than end a research relationship, in situations where Aboriginal community members are in disagreement, the research team will strive to resolve conflict towards achieving a significant degree of consensus.
- The research team agrees that it may be necessary for Aboriginal community members (investigators and participants) to seek advice and support from community elders and other community leadership.

Authorship

Criteria outlined by Huth (1986) will be used as guidelines for authorship of publication based on the findings of the research. The criteria recommend that: (1) all authors must make a substantial contribution to the conception, design, analysis, or interpretation of data; (2) authors must be involved in writing and revising the manuscript for intellectual content; and (3) authors must approve the final draft and be able to defend the published work. Those who have made other contributions to the work (e.g. data collection without interpretation, etc.) or only parts of the above criteria should be credited in the acknowledgements, but not receive authorship. Further,

- Research project staff may participate as authors provided that they fulfil the criteria outlined above.
- All members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation. Any one member of the research may further analyse, publish or present findings resulting from the above-mentioned research project with the agreement of the Principal Investigator and the other research team members.
- The explicit permission of an individual or organization must be sought prior to acknowledging their contribution in a paper or presentation.
- A research team member or a partner may chose to include a disclaimer if they do not agree with the content or views presented in a publication.

IN WITNESS WHEREOF, the parties hereto have executed this agreement.

(Date) _____ (Signature)

(Date) _____ (Signature)

(Date) _____ (Signature)

(Date) _____ (Signature)