



**Doing Good  
Health Research  
in Northern  
Indigenous  
Communities:**

**A Guide to  
Research Review**

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**Revised & Reprinted:** September 2012

**Funded by:** Kloshe Tillicum (formally Network Environment for Aboriginal Health Research BC & Western Arctic, CIHR/IAPH); Tri-territorial Health Access Funding (Operational Secretariat); CIHR Team Grant “Averting Chronic Diseases in Northern Populations”.

**Photo credits:** Katelyn Friendship & Marilyn Van Bibber

**Suggested citation:** Van Bibber, M. and George, A. (2012). Doing Good Health Research in Northern Indigenous Communities: A Guide to Research Review. Whitehorse Yukon: Arctic Institute of Community Based Research. 23pp.



The original paper written by M. Van Bibber and A. George in 2006 has been adapted for specific use by Yukon First Nations (2009) and for general use by northern Indigenous communities.

Northern Indigenous communities may wish to adapt the contents of this booklet into their own research review process to better align their own traditional knowledge and governance practices.

**Arctic Institute of Community-Based Research**  
(formerly Arctic Health Research Network-Yukon)

[www.aicbr.ca](http://www.aicbr.ca)

**ISBN:** 978-0-9809736-6-2



Arctic Institute of  
Community-Based Research  
YUKON, CANADA

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# Acknowledgements

The Arctic Institute of Community-Based Research would like to acknowledge the contribution of the Yukon First Nations' Health & Social Commission in the development of this 2012 booklet.

In 2008 and 2009, the Arctic Institute of Community-Based Research (then the Arctic Health Research Network-Yukon) met with the Yukon First Nations' Health & Social Commission to adapt a research review process document to incorporate Yukon First Nation communities' considerations. The result of that collaboration was the 2009 *Doing Good Research* paper by:



Marilyn Van Bibber (AHRN-YT), Anne George (UBC), Jody Butler Walker (AHRN-YT), Norma Kassi (AHRN-YT), Lori Duncan (CYFN), Lawrie Crawford (CTFN), Rachel Byers (LSCFN), Mary Kane (CAFN), Kelly Morris (TTC), Lucy McGinty (SFN), Deb Nagano (THFN), Reanna Sutton (VGFN), Sandy Washburn (FNNND), Jackie Johnny (WRFN), May Bolton (RRDC), Agnes Ball (KTC), Roberta Jules (LFN), Pat Martin (TKC), Robert Van Lieshout (KFN).

In 2008, 2009, and again in 2011, Yukon First Nation contributors to this document did so based on their knowledge and life experiences.

For more information about OCAP (Ownership, Control, Access, Possession) principles please contact the Department of Health & Social Development, CYFN or refer to the First Nations Information Governance Centre ([www.fnigc.ca](http://www.fnigc.ca)).

Thank you to Yukon First Nation Health Directors, CYFN staff, community participants, and others who contributed to the development of the "*Doing Good Health Research*" booklet. Mussi Cho.

# Dedication

We dedicate this booklet to Agnes Mills , a Vuntut Gwitchin elder, who has dedicated much of her life as an advocate for the well-being of Indigenous peoples across Canada. Agnes was born in Fort McPherson, Northwest Territories, while her parents were visiting relatives. The trip was made by dog team, and started Agnes' life long connection to the land and traditional ways.

Agnes was raised with the traditional values and knowledge of the land. As an Elder, Agnes continues to offer respect and caring as she shares her wisdom and her experiences, whether it is with a government bureaucrat, a corrections' inmate, or a First Nation leader.

Agnes is a firm believer in the importance of the traditional way of Indigenous peoples everywhere, as we continue to strive towards self-determination. She says those of us who work in the health field and those who are conducting research must look to our own traditional practices, knowledge, and to our stories. Agnes speaks about health research ethics as being spirit-centred. Agnes' manner and way of treating others is a living reflection of Yukon First Nation traditional values.



Mussi Cho, Agnes



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# Purpose & Background

This booklet is intended as a resource for northern Indigenous communities to use if they so wish. The purpose is to assist communities in ensuring that research is conducted ethically and according to community values. It is based on community input and a review of ethics principles, guidelines and tools developed in Canada and abroad. This booklet can guide the reader in understanding research processes and be an aide to reviewing research plans and proposals.



By understanding research processes and taking charge of reviewing the plans of researchers coming to the community, northern Indigenous communities can take control of how research is conducted in their communities. Across Canada, Indigenous health research guidelines and protocols are being developed. This booklet is not meant to replace the roles and responsibilities of communities who are developing or who have already developed their own research protocols. It is designed as an easy-access resource for communities to use when reviewing potential research projects in their community, if they want to use it.

This is a 'living document', which means it will continue to grow as new insights take place. It includes additional resources and links to resources for doing good Indigenous health research. While it has been written with northern communities in mind, the principles and processes are adaptable to other Indigenous communities.



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# Research Development

From time to time, Indigenous communities in Canada are involved in health-related research. They may be conducting their own research or may be invited to participate in research projects. Guidelines and policies can be used to screen, accept or reject, monitor, and prioritize what research is conducted within communities. Indigenous communities will then be in a better position to play a leading role in community-based health research.

Community participation in research review is not meant to be time consuming or to make research difficult for the researcher or the community. Rather it should create a clear and respectful research partnership between Indigenous and research communities that can only lead to good research practice and ultimately be a benefit to Indigenous health.

Developing research capacity at the community level can contribute to:

- Greater participation of northern Indigenous peoples in community-based research;
- Understanding the interrelationship between health and broader issues such as housing, economic status, governing systems and cultural practices and knowledge;
- The creation of knowledge of health status and health issues that can lead to improving our health and well-being;
- Research findings that can support negotiations for needed resources to develop programs and policies.

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# Principles

The 4 R's are general principles that can be adopted for research within northern Indigenous communities, and with Indigenous peoples. The 4 'R's of research reflect the northern cultural values of respect, caring and sharing.

- **Respect** is demonstrated toward Indigenous peoples' cultures and communities by valuing their diverse knowledge of health matters and respect towards health science by valuing scientific knowledge that contributes to community health and wellness.
- **Relevance** to culture and community is critical for the success of Indigenous health training and research.
- **Reciprocity** is accomplished through a two-way process of learning and research exchange. Both communities and researchers benefit from effective training and research relationships.
- **Responsibility** is empowering people to take action. It is fostered through active and ongoing meaningful participation.

(Institute for Aboriginal Health, 2011)

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# Ethical Guidelines

*The following statements are common themes found in many different ethics guidelines from regional, national and international sources. Indigenous communities may want to create their own ethical guidelines. These are offered as examples:*

- 
- Respect for human dignity.
  - Respect for northern Indigenous peoples' culture and community.
  - Recognition and respect for Indigenous peoples' jurisdiction.
  - Benefit to northern communities.
  - Free and informed consent from both individuals and community according to community-specific protocols.
  - Protect individual privacy and confidentiality.
  - Respect community confidentiality.
  - Full and meaningful participation in the research process.
  - All biological (blood and tissue) samples from Indigenous communities must be considered 'on loan' to researchers.
  - Research should build on the strengths of northern Indigenous peoples and their community.
  - Indigenous peoples' ownership and control of the research findings.
  - Capacity building as a reciprocal process from the beginning to the end.
  - Building research relationships is a partner responsibility.

(Adapted from Canada's Tri Council Policy Statement 2, 2010)

# Ethical Guidelines

- **Respect for human dignity.**

Respect for human dignity is the foundational principle for research ethics. This includes protection of the interests of the individual, including physical, psychological and cultural integrity. There is an obligation of researchers to protect the best interests of research participants.

- **Respect for northern Indigenous culture and community.**

Researchers must acknowledge and respect northern Indigenous worldviews, especially when seeking traditional or sacred knowledge. Respect means an understanding that there are rights and privileges associated with cultural and community knowledge, and therefore, appropriate ways that the knowledge is used. Each community or nation may have their own cultural values for guiding research.

- **Recognition and respect for Indigenous peoples' jurisdiction.**

Northern Indigenous peoples have rights and responsibilities over their intellectual and cultural property. Indigenous communities have the right to make decisions about research, to participate in all aspects of the research, to interpret the findings and the right to ownership of their own cultural and community knowledge. The rights of communities to own research data must always be with the assurance that individual privacy and confidentiality will be upheld.

- **Benefit to northern communities.**

Research topics should be relevant to the culture and community priorities of northern Indigenous communities. The results of research should have the potential to make a positive difference in Indigenous health and well-being. Benefits include greater capacity for conducting research, building positive research partnerships, and finding solutions and resources to address health conditions and issues. Researchers must ensure that the research process and any communication about the research will benefit and not harm northern Indigenous peoples and their communities.

# Ethical Guidelines

- **Free and informed consent from both individuals and community.**

Researchers must ensure that clear and unbiased information about the research process includes potential benefits, risks, the communication of the findings, as well as what happens to the individual data and grouped data from the research process. Both individuals and communities must be assured that they have a choice to participate or refuse without consequence. Community consent is sought prior to individual participant consent.

- **Protect individual privacy and confidentiality.**

Each individual who participates in research has the right to have his/her identity remain confidential. Data and findings must be reported in a manner that protects each and every research participant from being identified, unless this protection is waived.

- **Respect community confidentiality.**

Each community participating in a research project must have the choice on whether it will be identified in the research reports or findings. Respect and protection of Indigenous peoples' intellectual property should be stipulated in a research partner agreement. Dispute resolution should be guided by the advice of Elders.

- **Full and meaningful participation in the research process.**

Indigenous peoples must have opportunities to fully participate in all stages of the research process, from identifying the issues to be researched, the methods to be used in the research, decisions about the ethics and values associated with the research, the analysis of the findings and communication of those findings.

- **All biological samples (blood and tissue) from Indigenous communities must be considered 'on loan' to researchers.**

All blood or tissue samples taken during research must be considered "on loan" to researchers. Transfer or secondary analysis requires a new an ethics review board approval with specific consent from the individual and the community.



# Ethical Guidelines

- **Research should build on the strengths of northern Indigenous peoples and their community.**

Research that recognizes and builds on the strengths and responsibilities of the community or the individual are more in keeping with Indigenous cultural values. Culture has been identified time and again as a natural resource and strength of Indigenous communities, and therefore, has a significant role in achieving health and well-being.

- **Indigenous peoples' ownership and control of the research findings.**

Respect for northern Indigenous peoples' jurisdiction over their intellectual property is central to conducting health research in Indigenous communities. It acknowledges that communities own information collectively, in the same way that individuals own personal information. It respects Indigenous peoples' right to control and own research data. Research funding should include the cost of developing the necessary infrastructure and training for staff to build local capacity for stewardship of research data.

- **Capacity building is a reciprocal process.**

Building the capacity to do good research involves both community and research partners. Communities can gain knowledge about research, the research process and develop and implement skills to conduct and oversee research. Researchers can gain knowledge of the partner community, its culture, traditions, and protocols for conducting good research.

- **Building research relationships is a partner responsibility.**

Research partnerships based on mutual respect and collaboration provides an opportunity to enhance the quality of northern Indigenous health research. Developing a research relationship early in the research process is essential to the success of northern Indigenous health research.



# Rights of Research Participants

- For all participants:
  - Anonymity and confidentiality must be ensured.
  - All data must be stored in a locked cabinet and password protected files.
- No rights (to education, health care, social services or other services) can be lost because of participation in any research.
- Research findings must be reported to individual and community participants before they are reported anywhere else.
- Before participating in any research study, all individuals must be fully informed of the purpose, methods, time involved, and their rights as participants. Participants can agree by oral or written consent, and there must be evidence of this consent witnessed by at least one person.

(Adapted from Canada's Tri Council Policy Statement 2, 2010)



# Research Review Checklist

<b>Guiding Principles</b>	<b>Check List</b> (sample questions for the reviewer) The following sets of questions are examples of questions to assist the reviewer in assessing the merits of the research proposal.
Respect for human dignity	<ul style="list-style-type: none"> <li>• Are the research methods and processes respectful of the people taking part in the research?</li> <li>• Is there evidence that the researchers understand the existence of the worldviews of northern Indigenous people?</li> <li>• Does the research interfere with the dignity of individuals or communities participating in the research?</li> </ul>
Respect for northern Indigenous culture and community	<ul style="list-style-type: none"> <li>• Are there local cultural values to be considered in the research process?</li> <li>• Is there a process for securing consent from community leaders before seeking individual participation in the research?</li> <li>• Does the researcher understand the proper protocols for seeking community consent?</li> <li>• Will there be elders involved to offer guidance?</li> <li>• What is the timeline/timeframe for the project?</li> <li>• Are there provisions for community and/or individual concerns over and claims to intellectual property before the start of the research project?</li> </ul>
Recognition and respect for Indigenous peoples' jurisdiction	<ul style="list-style-type: none"> <li>• Does the research process respect northern Indigenous jurisdiction over the conduct of the research in their communities?</li> <li>• Is the use of the community's cultural and sacred knowledge addressed? (research agreement)</li> </ul>





# Research Review Checklist

Guiding Principles	Check List (sample questions for the reviewer)
Benefit to northern communities	<ul style="list-style-type: none"> <li>• Is the research relevant and a benefit to the research participants, local community, and Indigenous people in general?</li> <li>• How will your project benefit our community, people, future generations?</li> <li>• What are the immediate benefits?</li> <li>• Will the type of compensation or gifts be a benefit to and do no harm the participating individual?</li> <li>• Can any of the funds from the project be allocated to Indigenous organizations to do the research?</li> </ul>
Free and informed consent from both individuals and community	<ul style="list-style-type: none"> <li>• Is the consent procedure free of coercion?</li> <li>• Is the information clear and understandable?</li> <li>• Will the person be given adequate time to make his/her decision to participate?</li> <li>• Does the consent form contain the required elements to meet the standards of the research review committee?</li> <li>• Is there a process to get informed community consent?</li> <li>• Are there provisions for protecting the interests and dignity of children, institutionalized persons and persons with disabilities?</li> </ul>
Protect individual privacy and confidentiality	<ul style="list-style-type: none"> <li>• How do the researchers protect confidentiality and privacy?</li> <li>• How and where will the data be protected to ensure participants' safety during the research and after the research is completed?</li> <li>• Who will protect the data?</li> </ul>



# Research Review Checklist

Guiding Principles	Check List (sample questions for the reviewer)
Respect community confidentiality	<ul style="list-style-type: none"> <li>• Is there provision for the community to decide if it wants to maintain confidentiality or if it wants to be identified in any research publications and presentations?</li> </ul>
Full and meaningful participation in the research process	<ul style="list-style-type: none"> <li>• Has the community been given the option of a participatory research approach?</li> <li>• Is there a research ethics board, research committee or steering committee to guide the research process?</li> <li>• Does the community have opportunities in the interpretation of data and review of conclusions?</li> <li>• Are there plans to present the data back to participants in a manner acceptable to the community and the participants?</li> <li>• Is there ongoing communication with the community?</li> <li>• How will the participants and the partner community be acknowledged and given credit for their contributions to the research? (Note: privacy may apply)</li> </ul>
All biological (blood and tissue) samples from Indigenous communities must be considered 'on loan' to researchers	<ul style="list-style-type: none"> <li>• Are there provisions that acknowledge the ownership of biological samples?</li> <li>• Is there a clear understanding that secondary use of biological samples requires a new research ethics review process?</li> </ul>
Research should build on the strengths of northern Indigenous peoples and their community	<ul style="list-style-type: none"> <li>• Does the research focus on community and individual strengths?</li> </ul>



# Research Review Checklist

Guiding Principles	Check List (sample questions for the reviewer)
Indigenous peoples' ownership and control of the research findings	<ul style="list-style-type: none"> <li>• Are there provisions for who will own the grouped data?</li> <li>• Are there provisions for raw and grouped data?</li> <li>• Are the people who control the data trained to do so?</li> <li>• Are there policies and procedures in place for protecting data?</li> </ul>
Capacity building is a reciprocal process	<ul style="list-style-type: none"> <li>• Are there provisions in the research plan that allow for opportunities to participate in all aspects of the research?</li> <li>• Does the research process encourage reciprocal learning and capacity building? Will there be opportunities for mentorship?</li> <li>• Are there opportunities for the researcher to learn about cultural and community practices?</li> </ul>
Building research relationships is a partner responsibility	<ul style="list-style-type: none"> <li>• Is there a research agreement between the researchers and the community partner?</li> </ul>
Minimal risk	<ul style="list-style-type: none"> <li>• Is there a risk that individuals, groups, or communities will be stigmatized, lose prestige or self-esteem, or suffer economic loss because of the research?</li> <li>• Are there any risks of a physical nature?</li> <li>• Are the results likely to produce reactions of despair?</li> <li>• Is there a risk to preservation of confidentiality?</li> <li>• Are the risks reasonable in relation to the benefits?</li> </ul>

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# Procedures For Research Review Committees

## Committee Membership

- Committee members may be appointed by the Indigenous governing process or through community-based protocols.
- Committee should be representative of your community— with males and females, and include people representative of communities/regions (if committee represents more than one), age groups and include Elders.
- Some committee members who are experienced in research practices.

## Process

- 1. Committee
  - Decide membership
  - Enlist a Committee Chair
  - Train members in how to review protocols
- 2. Communicate with the northern Indigenous community and with the research team about the work of the Research Review Committee.
- 3. Develop all documents
  - Job description for Committee members
  - Review form for Committee members
  - Form letter to be sent to researchers
- 4. Template for Memorandum of Understanding between northern Indigenous communities and researchers.
  - Template for consent forms (with your logo)
  - Put all documents into a manual for each Research Review Committee member



# Bibliography

- Alberta ACADRE. Principles for Aboriginal Health Research. Available at: [www.acadre.ualberta.ca/](http://www.acadre.ualberta.ca/)
- Association of Canadian Universities for Northern Studies. (2003). Ethical Principles for the Conduct of Research in the North. Ottawa Canada.
- Brant Castellano M. (2004). Ethics in Aboriginal research. Journal of Aboriginal Health; 1:98-114.
- Caine V, Davis C, Jacobs T, & Letendre A. (2004) Ethics in the context of research and Indigenous people: A bibliography. Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health; 2(1). Available at: [www.pimatisiwin.com/online/?page\\_id=487](http://www.pimatisiwin.com/online/?page_id=487)
- Canadian Institutes of Health Research. (2009). CIHR Guidelines for Health Research Involving Aboriginal Peoples. Available at: <http://www.cihr-irsc.gc.ca/e/29134.html>
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada (TCPS 2). (2010). Research involving the First Nations, Inuit and Métis peoples of Canada. Chapter Nine in Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Ottawa Canada.
- Downie J, Cottrell B. (2001). Community-based research ethics review: Reflections on experience and recommendations for action. Health Law Review; 10(1): 8-17.
- Ermine, W., Sinclair, R., Browne, M. (2005). Kwayask itôtamowin: Indigenous Research Ethics. Indigenous Peoples' Health Research Centre; Saskatoon, Canada. Available at: <http://iphrc.ca/resources/archives>
- Ermine, W., Sinclair, R., Jeffery, B.. (2004). The Ethics of Research Involving Indigenous Peoples. Indigenous Peoples' Health Research Centre; Saskatoon, Canada. Available at: <http://iphrc.ca/resources/archives>
- First Nation of Na-Cho Nyak Dun, Tr'ondëk Hwëch'in, and Yukon Chamber of Mines. (2011). Engaging with Yukon First Nations and Communities: A Quick Reference Guide to Effective and Respectful Engagement Practices. Yukon Canada.
- First Nations Information Governance Centre. The First Nations Principles of OCAP. Available at: <http://fnigc.ca/ocap.html>
- George MA. (2011). Review of procedures for approval of health studies in northern Canada. Special Issue, International Journal of Circumpolar Health 70(4):354-362.
- George A, Daniel M, Green, L. (1998-1999). Appraising and funding participatory research in health promotion. International Quarterly of Community Health Education; 18(2): 181-197.
- Institute for Aboriginal Health. (2011). The 4R's of Aboriginal Health: Research, Relevance, Reciprocity, Responsibility. Adapted from: Kirkness, V. J. and R. Barnhardt (2001). First Nations and Higher Education: The Four R's- Respect, Relevance, Reciprocity, Responsibility. Available: [www.iah.ubc.ca/research/4rs.php](http://www.iah.ubc.ca/research/4rs.php)
- Inuit Tapiriit Kanatami. (2003). Negotiating research relationships: A guide for communities. Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health; 1(1): 17-25. Available at: [www.pimatisiwin.com/online/?page\\_id=12](http://www.pimatisiwin.com/online/?page_id=12)
- Kahnawake Schools Diabetes Prevention Project. (2007). Code of Research Ethics. Kahnawake Schools Diabetes Prevention Project; Kahnawá:ke, Quebec. Available at: [www.ksdpp.org](http://www.ksdpp.org)



# Bibliography

- Kirkness, VJ, Barnhardt R. (1991). First Nations and higher education: The four R's - respect, relevance, reciprocity, responsibility. *Journal of American Indian Education*; 30(3): 1-15.
- Macaulay AC, Delormier T, McComber AM, Cross EJ, Potvin LP, Paradis G, Kirby RL, Saad-Haddad C, Desrosiers S. (1998). Participatory research with native community of Kahnawake creates innovative code of research ethics. *Canadian Journal of Public Health*; 89(2):105-8.
- National Aboriginal Health Organization. (2007). Considerations and Templates for Ethical Research Practices. First Nations Centre of the National Aboriginal Health Organization; Ottawa Canada. Available at: [www.naho.ca/firstnations/publications/ethics/](http://www.naho.ca/firstnations/publications/ethics/)
- National Aboriginal Health Organization. (2007). OCAP: Ownership Control, Access and Possession. First Nations Centre of the National Aboriginal Health Organization; Ottawa Canada.
- National Aboriginal Health Organization. (2005). Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research. First Nations Centre of the National Aboriginal Health Organization; Ottawa Canada. Available at: [www.naho.ca/firstnations/publications/ethics/](http://www.naho.ca/firstnations/publications/ethics/)
- National Aboriginal Health Organization. (2003). Ethics Tool Kit. First Nations Centre of the National Aboriginal Health Organization; Ottawa Canada. Available at: [www.naho.ca/firstnations/publications/ethics/](http://www.naho.ca/firstnations/publications/ethics/)
- National Health and Medical Research Council. (2003). Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander Health Research. National Health and Medical Research Council; Canberra, Australia.
- National Health and Medical Research Council. (2005). Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander People About Research Ethics. National Health and Medical Research Council; Canberra, Australia.
- Nuu Chah Nulth Research Protocol (2009). Available at: [www.nearbc.ca/documents/2009/NTC-Protocolsand-Principles.pdf](http://www.nearbc.ca/documents/2009/NTC-Protocolsand-Principles.pdf)
- Patterson, M., Jackson, R., Edwards, N. (2006). Ethics in Aboriginal Research: Comments on Paradigms, Process and Two Worlds. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research*; 1: 47-61.
- RCAP Ethical Guidelines for Research (2005) Available at: [www.inchr.com/Doc/February05/RCAPethics.pdf](http://www.inchr.com/Doc/February05/RCAPethics.pdf)
- Schnarch B. (2004). Ownership, Control, Access and Possession (OCAP) or self-determination applied to research. *Journal of Aboriginal Health*; 1:80-95.
- Van Bibber, M., George, A., Butler Walker, J., Kassi, N., Duncan, L., Crawford, L., Byers, R., Kane, M., Morris, K., McGinty, L., Nagano, D., Sutton, R., Washburn, S., Johnny, J., Bolton, M., Ball, A., Jules, R., Martin, P., Van Lieshout, R. (2009). *Doing Good Research: A Guide for Research Review in Yukon First Nations Communities*. Yukon Canada: Arctic Institute of Community-Based Research. 16pp.
- Weijer C. (1999). Protecting communities in research: Philosophical and pragmatic challenges. *Cambridge Quarterly of Healthcare Ethics*; 8:501-513.
- Young-Ing G. (2006) Intellectual Property Rights, Legislated Protection, Sui Generis Models and Ethical Access in the Transformation of Indigenous Traditional Knowledge. Doctor of Philosophy thesis; University of British Columbia. Available at: <http://eprints.rclis.org/archive/00009591/>

# Abbreviations

- **AHRN-YT:** Arctic Health Research Network-Yukon
- **AICBR:** Arctic Institute of Community-Based Research
- **CAFN:** Champagne & Aisihik First Nations
- **CTFN:** Carcross Tagish First Nation
- **CYFN:** Council of Yukon First Nations
- **FNNND:** First Nation of Na'cho Nyak Dun
- **KDFN:** Kwanlin Dün First Nation
- **KFN:** Kluane First Nation
- **KTC:** Kaska Tribal Council
- **LFN:** Liard First Nation
- **LSCFN:** Little Salmon Carmacks First Nation
- **RRDC:** Ross River Dena Council
- **SFN:** Selkirk First Nation
- **TH:** Tr'ondëk Hwëch'in
- **TKC:** Ta'an Kwächän Council
- **TTC:** Teslin Tlingit Council
- **UBC:** University of British Columbia
- **VGFN:** Vuntut Gwitchin First Nation
- **WRFN:** White River First Nation
- **YFNHSC:** Yukon First Nations' Health & Social Commission





# Appendices





# Considerations and Templates For Ethical Research Practices

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## Appendix B - Template for a Collaborative Research Agreement <sup>i</sup>

Project title \_\_\_\_\_

THIS COLLABORATIVE RESEARCH AGREEMENT is made this \_\_\_\_ day of \_\_\_\_, 2006.

BETWEEN:

Principal Researchers(s)

Name(s): \_\_\_\_\_

Supporting Agency \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Facsimile: \_\_\_\_\_

Email: \_\_\_\_\_

AND

\_\_\_\_\_ First Nation Community

Contact person(s): \_\_\_\_\_

Organization: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Facsimile: \_\_\_\_\_

Email: \_\_\_\_\_

The principal researchers, as named, and the \_\_\_\_\_ First Nation agree to conduct the named collaborative research project in accordance with the guidelines and conditions described in this document.

*These pages can be photocopied to be shared or re-used as necessary.*

## 1. Purpose of the Research Project

*This section should describe the general topic that is being researched, and also the purpose of doing the research (e.g. to increase awareness/understanding, enhance well-being, improve programs, etc.). A statement of purpose is usually fairly brief (2-5 sentences) and not too specific.*

### **Sample text:**

The purpose of this research project, as discussed with and understood by the \_\_\_\_\_ First Nation in the community of \_\_\_\_\_, is to investigate \_\_\_\_\_

The results of this research may be used to \_\_\_\_\_

## 2. Scope of the Project

*This section provides a more specific and detailed description of the project. It should cover the following areas:*

- *Specific research objectives or question(s);*
- *Types of information that will be gathered (e.g. statistics, interviews, etc.);*

### **Sample text:**

The project has the following objectives and/or aims to answer the following questions: \_\_\_\_\_

In order to meet the objectives or answer the questions stated above, the following types of information will be gathered:

## 3. Methods and Procedures

*This section describes how research data will be gathered, recorded, analyzed and reported. Issues that should be addressed in this section are listed below. Involvement of First Nation community members in the project is addressed in this section, but a separate section could be created to deal with that issue since it is usually an important consideration for communities.*

- *Research (or data-gathering) methods; depending on the nature of the project, these might include: collecting information/statistics from databases; collecting environmental samples; conducting surveys, interviews or focus groups;*
- *The extent or amount of data to be obtained should be specified (e.g. statistical variables, number of interviews/surveys, number of samples, etc.) and explained;*
- *The role of community members in the research (or data-gathering) phase (as participants in interviews, etc. and/or as paid researchers, fieldworkers or guides);*

- *Procedures for obtaining consent (individual or collective) must be described in detail;*
- *Methods to be used for recording and storing data;*
- *Procedures for ensuring confidentiality and security of data;*
- *Methods of analysis or interpretation of data to generate findings and conclusions;*
- *Opportunity for community members or community researchers to participate in data analysis, or to verify the results of the analysis;*
- *Preparation of the final report; will community members have an opportunity to revise and approve it before it is finalized?*
- *Format for presenting findings to the general public and the community (e.g. article, final report, presentation, etc.)*

**Sample text:**

Data will be gathered using the following methods or procedures: \_\_\_\_\_

\_\_\_\_\_

The amount of data that is required for this project is \_\_\_\_\_.

This number/amount is required because \_\_\_\_\_.

Community members will assist or participate with the data-gathering phase in the following ways:

\_\_\_\_\_

\_\_\_\_\_

Individual consent to participate in the project will be obtained in the following way: \_\_\_\_\_

\_\_\_\_\_

Participants have the right to withdraw from the project at any time for any reason. In this case, that participant's data will be destroyed.

Research data will be stored in the following ways: \_\_\_\_\_

\_\_\_\_\_

The following persons will have access to research data: \_\_\_\_\_

Confidentiality of research data (if desired) will be ensured in the following ways: \_\_\_\_\_

\_\_\_\_\_

Data will be analyzed or interpreted through the following methods: \_\_\_\_\_

\_\_\_\_\_

Community researchers/participants will participate in the analysis of data, or the verification of results, in the following ways: \_\_\_\_\_

The final research report will be submitted to the community for review and approval.

Research findings will be presented to the community in a language and format that is clear and comprehensible to community members.

Research findings will be presented to the community in the following formats: \_\_\_\_\_

Research findings will be presented to the general public and/or any other audience in the following formats: \_\_\_\_\_

#### **4. Expected Outcomes, Benefits and Risks**

*This section sets out the expected outcomes and benefits of the research project. It is important to be clear and honest about expected benefits for both the researchers and the community. Benefits for the principal researchers may include financial gain (from publication, etc.) or indirect financial benefit through enhancement of professional status (to an individual or research institution). Benefits to the community may include the generation of information that will support future funding applications or that will enhance community programs/services; education and/or training for community members; or direct financial compensation to community researchers and/or participants.*

*Risks to the community as a result of the project should also be considered, as should any measure that could be taken to minimize those risks. These may include: environmental impacts; invasion of personal or collective privacy; portrayal of the community in a negative way and; disruption of other important community projects or issues.*

##### **Sample text:**

The expected outcomes of this research project are: \_\_\_\_\_

The project will benefit the principal (external) researchers in the following ways: \_\_\_\_\_

The project will benefit the community (individually or collectively) in the following ways: \_\_\_\_\_

The project poses the following risks to the community: \_\_\_\_\_

Measures that will be taken to minimize these risks are: \_\_\_\_\_



## 5. Obligations and Responsibilities

*This section is not specific to a particular research project. It describes general obligations and responsibilities of each partner (community, external researchers and community-based researchers) in a community-based research project through all phases including research design, implementation, data collection and analysis and the dissemination of information.*

### External Research Partner

- To do no harm to the community.
- To involve the community in active participation of the research process and to promote it as a community-owned activity.
- To ensure the research's design, implementation, analysis, interpretation, reporting, publication and distribution of its results are culturally relevant and in compliance with the standards of competent research.
- To undertake research that will contribute something of value to the community.
- To ensure that new skills are acquired by community members, such as research design, planning, data collection, storage, analysis, interpretation and so on.
- To be stewards of the data until the end of the project if requested or appropriate.
- To promote the dissemination of information to society at large if desired and appropriate through both written publications and oral presentations.
- To be involved in any future analysis of the data after the data is returned to the community, if requested.
- To abide by any local laws, regulations and protocols in effect in the community or region, and to become familiar with the culture and traditions of the community.
- Within their respective roles as researchers and community representatives, to advocate and address health, social or other issues that may emerge as a result of the research.
- To ensure that the community is fully informed in all parts of the research process, including its outcomes through publications and presentations, and to promptly answer questions that may emerge regarding the project and its findings.
- To communicate equally with the other partners in all issues arising in the project.

- To ensure that research carried out is done in accordance with the highest standards, both methodologically and from a First Nations cultural perspective.
- To support the community by providing resources as a matter of priority (e.g., research funding to support community research coordinator).
- To abide by their own professional standards, their institution's guidelines for ethical research and general standards of ethical research.

### **Community-Based Researcher**

In addition to the obligations listed for the external research partners, the community researcher is obligated:

- To provide a link between the research project team and other community members, and provide relevant, timely information on the project.
- To place the needs of the community as a first priority in any decision where the community researcher's dual roles of community member and researcher may be in conflict.
- In situations where a research project is promoting healthy lifestyles or practices, to promote the intervention objectives of the project by working closely with community health, social and/or education professionals.
- To be stewards of the data until the end of the project if requested or appropriate.

### **Community Partner**

- First and foremost, to represent the interests, perspectives and concerns of community members and of the community as a whole.
- To ensure that research carried out is done in accordance with the highest standards, both methodologically and from a First Nations cultural perspective.
- To communicate the results of the research to other communities, and to share ideas as well as program and service development for mutual benefit and involvement.
- To serve as the guardian of the research data during and/or after completion of the project.
- To offer the external and community researchers the opportunity to continue data analyses before the data are offered to new researchers.

## 6. Funding

*This section identifies funding sources and sets out the responsibilities of all partners with respect to funding requirements.*

### **Sample text:**

The principal researchers have acquired funding and other forms of support for this research project from these sources: \_\_\_\_\_

The funding agencies have imposed the following criteria, disclosures, limitations and reporting responsibilities on the principal researchers: \_\_\_\_\_

The community partner has the following responsibilities with respect to funding requirements\*:

\_\_\_\_\_

*\*In most cases, responsibility to fulfill funding and reporting requirements falls primarily to the principal researchers, so this may not be applicable.*

## 7. Dissemination of Results

*This section should identify all the stakeholders (e.g. communities, the academic sector, funding bodies, professional bodies, government departments, etc.), to which research results will be disseminated. The methods for dissemination should also be described.*

*You may want to consider the degree of control that the community has over future publication or dissemination of research results.*

### **Sample text:**

Research results will be disseminated to the following stakeholders: \_\_\_\_\_

Research results will be disseminated in the following manner: \_\_\_\_\_

Any future publication or dissemination of research results, beyond what is described in this agreement, shall not be undertaken without consultation with the \_\_\_\_\_ First Nation community.

## 8. Data Ownership and Intellectual Property Rights

*The data gathered or produced through the research project is distinct from the research results. The First Nation community should clearly affirm ownership of its data, as well as any associated intellectual property rights. Conditions of data stewardship and use of data after completion of the research project should be considered by the community, but do not need to be specified in the research agreement since this is an internal protocol to be determined at the community's discretion.*

### **Sample text:**

The individual owns his or her personal information while the \_\_\_\_\_ First Nation owns the collective data.

The \_\_\_\_\_ First Nation retains all intellectual property rights (including copyright), as applicable, to the data offered under this agreement.

Access and stewardship of the collective data are negotiated and determined by the First Nation.

## **9. Communication**

*Guidelines for internal and external communication should be established in this section. 'Internal communication' means communication between research partners names in this agreement, while 'external communication' refers to communication about the project to other interested parties such as the media.*

### ***Sample text:***

Communication on all aspects of the research, including progress reports to the community, will be ensured in the following ways: \_\_\_\_\_

In the case of media inquiries during or after the project, designated spokespersons are:  
\_\_\_\_\_

The community will be the first to receive research results and the first invited to provide input and feedback on the results. The results should be presented in a format that is language appropriate and accessible to the community. Results will not be released without the approval of the community.

At the end of the study, the research partners agree to participate in community meetings to discuss the results and their implications.

## **10. Dispute Resolution**

*This section sets out the process for addressing concerns or resolving disputes related to the implementation, interpretation or release of research data and/or findings.*

### ***Sample text:***

In the event that a dispute arises out of or relates to this research project, both parties agree first to try in good faith to settle the dispute by mediation administered by an agreed upon neutral party before resorting to arbitration, litigation or some other dispute resolution procedure. A mediator will assist the parties in finding a resolution that is mutually acceptable.

If a dispute cannot be resolved to the satisfaction of both parties, the research project may be terminated according to the terms described below.

## 11. Term and Termination

*This section notes the duration of the project and sets out the course of action to be followed if either party to the agreement wishes to terminate the research project.*

### ***Sample text:***

This agreement shall have an effective date of \_\_\_\_\_ and shall terminate on \_\_\_\_\_. This agreement may be terminated by the written notification of either party.

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<sup>i</sup>Adapted from: World Health Organization, *Indigenous peoples and participatory health research: Preparing research agreements*, Annex B: Example of a research agreement concluded between CINE and an indigenous community in Canada ([www.who.int/ethics/indigenous\\_peoples/en/print.html](http://www.who.int/ethics/indigenous_peoples/en/print.html)) and; Masuzumi, B., and Quirk, S, *Dene Tracking. A participatory research process for Dene/Métis communities: Exploring community-based research concerns for Aboriginal northerners* (Yellowknife, NT: Dene Nation, 1993) p. 14-16.

## SAMPLE CONSENT FORM

**Name:**

**Address:**

**Phone #:**

**Date:**

**Time:**

Re: \_\_\_\_\_ (*project name* \_\_\_\_\_)

The purpose of this project is to \_\_\_\_\_  
\_\_\_\_\_ and the information  
collected by me will be used for \_\_\_\_\_

The data obtained from the study by \_\_\_\_\_ (*organization/ research institution*) \_\_\_\_\_  
will be strictly used for the purposes of said research. My name will not appear in any  
report, unless I give consent. Moreover, confidentiality will be protected and results will  
only be publically presented in a general fashion. Materials (research data) will also be  
given to the \_\_\_\_\_ (*First Nation*) \_\_\_\_\_ archive for holding (i.e. interview transcripts)  
and future use.

My participation will consist essentially of attending \_\_\_\_\_ (*focus group/ interview/  
etc.*) \_\_\_\_\_ with the researcher(s). This will take \_\_\_\_\_ (length of time) \_\_\_\_\_. The information  
will be collected and recorded on a digital tape recorder (if I provide consent) and by  
personal note-taking. If I request it, translation services, paid by the researcher will be  
provided to complete the research. It is intended that there is little risk in participating in  
this project and I should feel comfortable with its nature at all times.

I understand that my confidentiality will be respected. If there are circumstances where the  
researcher wishes to use a direct quote from my interview in any publication, they will first  
ask my permission before doing so and I will have the opportunity to decline without  
prejudice.

My participation in this project is voluntary and I am free to withdraw from the project at  
any time, before or during an interview, refuse to participate and refuse to answer  
questions. I understand that my withdrawal will bear no consequences and no judgements  
or prejudice will be held against me.

If I have any questions about the conduct of the research project, I may contact any of the  
research team members. \_\_\_\_\_

## SAMPLE CONSENT FORM

By signing below, I *(participant name)* agree that I have been fully informed, understand the nature of the project, and agree to participate.

I have signed two copies of this form-one for me to keep.

\_\_\_\_\_  
Signature of Respondent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

I give \_\_\_\_\_ *(organization/ research institution)* consent to use my photograph(s) for research materials, presentations, etc.

**YES**

**No**

# TCPS2

TRI-COUNCIL POLICY STATEMENT

# Ethical Conduct for Research Involving Humans

2010

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Canadian Institutes of Health Research  
Natural Sciences and Engineering Research Council of Canada  
Social Sciences and Humanities Research Council of Canada

Please cite this document as follows:

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2010.

Note: For the most recent information on amendments, please consult the official online version of the TCPS at [www.pre.ethics.gc.ca](http://www.pre.ethics.gc.ca).

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Catalogue No: MR21-18/2010E-PDF  
ISBN 978-1-100-17237-81



# Chapter 9

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## RESEARCH INVOLVING THE FIRST NATIONS, INUIT AND MÉTIS PEOPLES OF CANADA

### **Introduction**

#### **Preamble**

This chapter on research involving Aboriginal peoples in Canada, including Indian (First Nations<sup>1</sup>), Inuit and Métis peoples, marks a step toward establishing an ethical space for dialogue on common interests and points of difference between researchers and Aboriginal communities engaged in research.

First Nations, Inuit and Métis communities have unique histories, cultures and traditions. They also share some core values such as reciprocity – the obligation to give something back in return for gifts received – which they advance as the necessary basis for relationships that can benefit both Aboriginal and research communities.

Research involving Aboriginal peoples in Canada has been defined and carried out primarily by non-Aboriginal researchers. The approaches used have not generally reflected Aboriginal world views, and the research has not necessarily benefited Aboriginal peoples or communities. As a result, Aboriginal peoples continue to regard research, particularly research originating outside their communities, with a certain apprehension or mistrust.

The landscape of research involving Aboriginal peoples is rapidly changing. Growing numbers of First Nations, Inuit and Métis scholars are contributing to research as academics and community researchers. Communities are becoming better informed about the risks and benefits of research. Technological developments allowing rapid distribution of information are presenting both opportunities and challenges regarding the governance of information.

This chapter is designed to serve as a framework for the ethical conduct of research involving Aboriginal peoples. It is offered in a spirit of respect. It is not intended to override or replace ethical guidance offered by Aboriginal peoples themselves. Its purpose is to ensure, to the extent possible, that research involving Aboriginal peoples is premised on respectful relationships. It also encourages collaboration and engagement between researchers and participants.

Building reciprocal, trusting relationships will take time. This chapter provides guidance, but it will require revision as it is implemented, particularly in light of the ongoing efforts of Aboriginal peoples to preserve and manage their collective knowledge and information generated from their communities. The Agencies – the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC), and the Social Sciences and Humanities Research Council (SSHRC) – are committed to the continued evolution of this Policy, as noted in the Introduction. As the Policy comes into effect, the approach of engaging communities will be

applied not only to research projects but also to the further development of the Policy itself to ensure that it remains a living document.

This chapter forms an integral part of this Policy to which institutions eligible to administer and receive research funding from any of the three research agencies agree to adhere as a condition of funding (see the *Memorandum of Understanding on the Roles and Responsibilities in the Management of Federal Grants and Awards*).<sup>2</sup> It has drawn on prior work, both within Canada and internationally, that recognizes the interests of Aboriginal peoples who participate in research and are affected by its results. Some of that work has been done by the three agencies responsible for this Policy. In particular, the CIHR and its Institute of Aboriginal Peoples' Health have engaged in extensive dialogue with community partners to develop the CIHR *Guidelines for Health Research Involving Aboriginal People*. The CIHR Guidelines remain an important source of additional guidance for health research involving Aboriginal peoples in Canada.

SSHRC and NSERC, likewise, have developed program guidelines for research involving Aboriginal peoples and issues. Aboriginal entities at local, regional and national levels have published and implemented principles and codes governing research practice – including ethical protections – that emphasize collective rights, interests and responsibilities.

This Policy provides guidance for research involving humans, as defined in Chapter 2. Other guidelines specific to particular programs, research domains and community settings may elaborate on the processes set out herein, or may address ethical concerns of broader scope than those covered in this Policy. Researchers and research ethics boards (REBs) are advised to consult reference documents that apply to their research undertaking. Examples of relevant resources are listed under References at the end of this chapter.

Neither this Policy nor this chapter are meant to reflect or introduce any change to other Government of Canada policies with respect to the issues addressed in this chapter.

### **Context**

The existing Aboriginal and treaty rights of the Aboriginal peoples of Canada, that is, the Indian, Inuit and Métis peoples of Canada, were recognized and affirmed in the *Constitution Act, 1982*.<sup>3</sup>

This chapter acknowledges the unique status of the Aboriginal peoples of Canada. It interprets how the value of respect for human dignity and the core principles of Respect for Persons, Concern for Welfare, and Justice (as articulated in Chapter 1) apply to research involving Aboriginal peoples. It accords respect to Aboriginal peoples' knowledge systems by ensuring that the various and distinct world views of Indian, Inuit and Métis peoples are represented in planning and decision making, from the earliest stages of conception and design of projects through to the analysis and dissemination of results. It affirms respect for community customs and codes of research practice to better ensure balance in the relationship between researchers and participants, and mutual benefit in researcher-community relations.

The purpose of this chapter specifically, and the Policy in general, is to provide guidance to researchers on the ethical conduct of research involving Aboriginal peoples.

The desire to conserve, reclaim and develop knowledge specific to First Nations, Inuit and Métis communities, and to benefit from contemporary applications of traditional knowledge, is a motivating force in community initiatives to assume a decisive role in research. The guidance provided in this chapter is based on the premise that engagement with community is an integral part of ethical research involving Aboriginal peoples.

This Policy acknowledges the role of community in shaping the conduct of research that affects First Nations, Inuit and Métis communities. The Policy also respects the autonomy of individuals to decide whether they will participate in research in accordance with Articles 3.1 to 3.6. Articles in this chapter give guidance for balancing individual and collective interests. In light of the diversity within and among First Nations, Inuit and Métis communities, and the ongoing development of community codes of research practice by these communities at the local, regional and national level, ethical review of a proposed project shall be attentive to the specific context of the project and the community involved (see Articles 9.8 and 9.9).

## **A. Key Concepts and Definitions**

Definitions of key concepts used in this chapter are provided to assist in applying the guidance in this Policy (see Chapter 1 regarding the scope of definitions used in this Policy) and to facilitate dialogue between researchers and Aboriginal communities. Since there is not universal agreement on the meaning of some terms, the definitions provided are intended for the purposes of this Policy only. This terminology will require periodic revision, particularly in light of the ongoing debate on the terms of art used in international and domestic contexts. This is in keeping with a commitment to the continued evolution of this Policy.

- **Aboriginal peoples** – include persons of Indian, Inuit or Métis descent regardless of where they reside and whether or not their names appear on an official register. The term “Aboriginal” fails to reflect the distinctions among First Nations, Inuit and Métis peoples, who have their own histories, cultures and languages, so an attempt has been made to limit use of the term in this Policy to instances where a global term is appropriate. Indian peoples commonly identify themselves by distinct nation names such as Mi’kmaq, Dene or Haida, and as First Nations. In the international context, the term comparable to Aboriginal peoples is Indigenous peoples.
- **Community** – describes a collectivity with shared identity or interests, that has the capacity to act or express itself as a collective. In this Policy, a community may include members from multiple cultural groups. A community may be territorial, organizational or a community of interest. “Territorial communities” have governing bodies exercising local or regional jurisdiction (e.g., members of a First Nations resident on reserve lands). “Organizational communities” have explicit mandates and formal leadership (e.g., a regional Inuit association or a friendship centre serving an urban Aboriginal community). In both territorial and organizational communities, membership is defined and the community has designated leaders. “Communities of interest” may be formed by individuals or organizations who come together for a common purpose or undertaking, such as a commitment to conserving a First Nations language. Communities of interest are informal communities

whose boundaries and leadership may be fluid and less well-defined. They may exist temporarily or over the long term, within or outside of territorial or organizational communities.

An individual may belong to multiple communities, both Aboriginal and non-Aboriginal (e.g., as a member of a local Métis community, a graduate students' society and a coalition in support of Aboriginal rights). An individual may acknowledge being of First Nations, Inuit or Métis descent but not identify with any particular community. How individuals define which of their community relationships are most relevant will likely depend on the nature of the research project being proposed.

- Community customs and codes of research practice – may be expressed in written or oral form. Consistent with the world views of particular First Nations, Inuit and Métis peoples, community customs and codes of research practice may embody kinship networks and responsibilities that include multi-generational obligations to ancestors and future generations. Ethical obligations often extend to respectful relations with plant, animal and marine life.
- Community engagement – is a process that establishes interaction between a researcher or research team, and the Aboriginal community relevant to the research project. It signifies a collaborative relationship between researchers and communities, although the degree of collaboration may vary depending on the community context and the nature of the research. The engagement may take many forms including review and approval from formal leadership to conduct research in the community, joint planning with a responsible agency, commitment to a partnership formalized in a research agreement, or dialogue with an advisory group expert in the customs governing the knowledge being sought. The engagement may range from information sharing to active participation and collaboration, to empowerment and shared leadership of the research project. Communities may also choose not to engage actively in a research project, but simply to acknowledge it and register no objection to it.
- First Nations, Inuit and Métis lands – include Indian reserves, Métis settlements, and lands governed under a self-government agreement or an Inuit or First Nations land claim agreement.
- Indigenous knowledge – see traditional knowledge, below.
- Indigenous peoples – a term used in international or scholarly discourse; there is no consensus on the definition of the term “indigenous.” In some countries, other terms may be used. Self-identification is a fundamental criterion for defining Indigenous peoples.<sup>4</sup>
- Traditional knowledge – the knowledge held by First Nations, Inuit and Métis peoples, the Aboriginal peoples of Canada. Traditional knowledge is specific to place, usually transmitted orally, and rooted in the experience of multiple generations. It is determined by an Aboriginal community's land, environment, region, culture and language. Traditional knowledge is usually described by Aboriginal peoples as holistic, involving body, mind, feelings and spirit. Knowledge may be expressed in symbols, arts, ceremonial and everyday practices, narratives and, especially, in relationships. The word tradition is not necessarily

synonymous with old. Traditional knowledge is held collectively by all members of a community, although some members may have particular responsibility for its transmission. It includes preserved knowledge created by, and received from, past generations and innovations and new knowledge transmitted to subsequent generations. In international or scholarly discourse, the terms traditional knowledge and Indigenous knowledge are sometimes used interchangeably.

## **B. Interpreting the Ethics Framework in Aboriginal Contexts**

Chapter 1 identifies three principles that express the core ethical value of respect for human dignity – Respect for Persons, Concern for Welfare, and Justice. The three core principles are interpreted in this chapter as follows:

**Respect for Persons** is expressed principally through the securing of free, informed and ongoing consent of participants. The concerns of First Nations, Inuit and Métis for their continuity as peoples with distinctive cultures and identities have led to the development of codes of research practice that are in keeping with their world views. Aboriginal codes of research practice go beyond the scope of ethical protections for individual participants, and extend to the interconnection between humans and the natural world, and include obligations to maintain, and pass on to future generations, knowledge received from ancestors as well as innovations devised in the present generation.

Historically, the well-being of individual participants has been the focus of research ethics guidelines. In this Policy, the principle of **Concern for Welfare** is broader, requiring consideration of participants and prospective participants in their physical, social, economic and cultural environments, where applicable, as well as concern for the community to which participants belong. This Policy acknowledges the important role of Aboriginal communities in promoting collective rights, interests and responsibilities that also serve the welfare of individuals.

Aboriginal peoples are particularly concerned that research should enhance their capacity to maintain their cultures, languages and identities as First Nations, Inuit or Métis peoples, and to support their full participation in, and contributions to, Canadian society. The interpretation of Concern for Welfare in First Nations, Inuit and Métis contexts may therefore place strong emphasis on collective welfare as a complement to individual well-being.

**Justice** may be compromised when a serious imbalance of power prevails between the researcher and participants. Resulting harms are seldom intentional, but nonetheless real for the participants. In the case of Aboriginal peoples, abuses stemming from research have included: misappropriation of sacred songs, stories and artefacts; devaluing of Aboriginal peoples' knowledge as primitive or superstitious; violation of community norms regarding the use of human tissue and remains; failure to share data and resulting benefits; and dissemination of information that has misrepresented or stigmatized entire communities.

Where the social, cultural or linguistic distance between the community and researchers from outside the community is significant, the potential for misunderstanding is likewise significant. Engagement between the community involved and researchers, initiated prior to recruiting

participants and maintained over the course of the research, can enhance ethical practice and the quality of research. Taking time to establish a relationship can promote mutual trust and communication, identify mutually beneficial research goals, define appropriate research collaborations or partnerships, and ensure that the conduct of research adheres to the core principles of Respect for Persons, Concern for Welfare – which in this context includes welfare of the collective, as understood by all parties involved – and Justice.

### **Research Involving Indigenous Peoples in Other Countries**

Although the present chapter addresses research involving Aboriginal peoples in Canada, researchers, REBs, participants and the research community at large may find the guidance articulated here useful when undertaking research or reviewing a proposal involving Indigenous peoples in other countries who endorse collective decision making as a complement to individual consent. It is critically important, however, to seek local guidance in the application or adaptation of this Policy to Indigenous peoples outside of Canada.

For considerations that apply to research conducted in another country, see Chapter 8, Section B.

## **C. Applying Provisions of This Policy in Aboriginal Contexts**

### **Requirement of Community Engagement in Aboriginal Research**

**Article 9.1** Where the research is likely to affect the welfare of an Aboriginal community, or communities, to which prospective participants belong, researchers shall seek engagement with the relevant community. The conditions under which engagement is required include, but are not limited to:

- (a) research conducted on First Nations, Inuit or Métis lands;
- (b) recruitment criteria that include Aboriginal identity as a factor for the entire study or for a subgroup in the study;
- (c) research that seeks input from participants regarding a community’s cultural heritage, artefacts, traditional knowledge or unique characteristics;
- (d) research in which Aboriginal identity or membership in an Aboriginal community is used as a variable for the purpose of analysis of the research data; and
- (e) interpretation of research results that will refer to Aboriginal communities, peoples, language, history or culture.

**Application** Paragraph (a) refers to First Nations, Inuit and Métis lands that include Indian reserves, Métis settlements and lands governed under a self-government agreement or an Inuit or First Nations land claim agreement. Researchers should become informed about formal rules or oral customs that may apply in accordance with a particular First Nations, Inuit or Métis authority. In different jurisdictions, research activities may be regulated in various ways.

Paragraph (c) refers to cultural heritage, which includes, but is not limited to, First Nations, Inuit and Métis peoples' relations with particular territories, material objects, traditional knowledge and skills, and intangibles that are transmitted from one generation to the next (e.g., sacred narratives, customs, representations or practices). Cultural heritage is a dynamic concept, in that materials, knowledge and practices are continuously adapted to the realities of current experience.

Cultural heritage research such as archaeological research involving burial sites or sacred landscapes and handling of artefacts may raise ethical obligations important to the Aboriginal community that may not be addressed in academic research proposals. Researchers and communities should agree in advance on how to reconcile or address these divergent perspectives (see Articles 9.8 and 9.12).

Appropriation of collective knowledge, treatment of such knowledge as a commodity to be traded, or making unauthorized adaptations for commercial purposes, may cause offence or harm to communities from which the knowledge originates. Such conduct has prompted initiatives in various countries and international agencies to address unethical, unfair, and inequitable treatment of traditional knowledge and knowledge holders (see Article 9.18).

Paragraph (e) refers to both primary collection of research data and secondary use of information collected originally for a purpose other than the current research purpose (see Article 2.4 and Chapter 5, Section D). Articles 9.20 to 9.22 address community engagement and individual consent for secondary use of identifiable information and human biological material for research purposes.

## **Nature and Extent of Community Engagement**

**Article 9.2** The nature and extent of community engagement in a project shall be determined jointly by the researcher and the relevant community, and shall be appropriate to community characteristics and the nature of the research.

**Application** Diversity among and within communities makes generalizations about the form of community engagement inappropriate. Diversity within Aboriginal communities may encompass differences in levels of formal education and employment, mobility, generational differences and intermarriage with non-Aboriginal persons. This diversity increases the importance of clarifying mutual expectations and obligations with the community, and incorporating them into a research agreement.

Community engagement as defined in this Policy can take varied forms. In geographic and organizational communities that have local governments or formal leadership, engagement prior to the recruitment of participants would normally take the form of review and approval of a research proposal by a designated body. In less structured situations (e.g., a community of interest), a key consideration for researchers, prospective participants and REBs is determining the nature and extent

of community engagement required. In some situations, if the REB is satisfied that participants are not identified with a community or that the welfare of relevant communities is not affected, the REB may waive the requirement of a community engagement plan (see Article 9.10). In these cases, consent of individuals is sufficient to participate.

Communities lacking the infrastructure to support pre-research community engagement should not be deprived of opportunities to participate in guiding research affecting their welfare (see Article 9.14).

The following list, which is not exhaustive, provides examples to illustrate the forms of community engagement that might be appropriate for various types of research.

- 1) Research directly involving a community on First Nations, Inuit or Métis lands with a formal governance structure. For example, a project that examines the incidence of diabetes in Pond Inlet, Nunavut, or the impact on Inuit health of contaminants in animals and plants used for country food.
  - Permission of the Nunavut Research Institute that carries authority to approve research in Nunavut is required. Agreement of the hamlet council in Pond Inlet will normally be a condition of approval. The local health committee may co-manage the project.
- 2) Research involving Aboriginal people who comprise a sizeable proportion of the study or community and where Aboriginal-specific conclusions are intended. For example, a comparative study of access to public housing in Prince Albert, Saskatchewan.
  - First Nations in the district, represented by their tribal council, the local Métis association, and urban Aboriginal and women's organizations may partner with the Prince Albert city council to sponsor, implement and use the results of the housing study.
- 3) Research focusing on a larger community that is known to include Aboriginal people (regardless of their proportion), and where Aboriginal-specific conclusions are anticipated. For example, a study of student retention in high schools in the Sault Ste. Marie district of Ontario.
  - A committee representing First Nations, Métis organizations and urban Aboriginal people whose children may be affected by the study may be convened to advise the District Board of Education and the researchers involved.
- 4) Research involving Aboriginal people who comprise a sizeable proportion of the larger community that is the subject of research even if no Aboriginal-specific conclusions will be made. For example, research on employment



development programs serving residents of the inner city of Winnipeg in Manitoba.

- Aboriginal service agencies or political organizations may be engaged to help recruit Aboriginal participants and secure community representation on an oversight committee, and to ensure cultural sensitivity in collecting and interpreting data on employment program impacts.
- 5) Interviewing a sample of individuals of Aboriginal ancestry across Canada on the impact of a policy on their lives, where the results are not attributable to, or likely to affect, the community or communities with which they may identify. For example, survey research on the implementation of *Indian Act* provisions requiring ministerial approval of an “Indian’s” will.
- First Nations, Inuit and Métis persons, whether or not they identify as members of an Aboriginal community, enjoy freedom of expression as does any citizen. They are free to consent and to participate in research projects that they consider to be of personal or social benefit. If the project is unlikely to affect the welfare of the individuals’ communities, local community engagement is not required under this Policy. The necessity or desirability of engaging regional or national representatives of Aboriginal communities in policy research may, however, be determined by other considerations.
- 6) Natural sciences research on First Nations, Inuit or Métis lands where Aboriginal people may act as co-investigators, or benefit from findings. For example, research focusing exclusively on contaminants in animals or plants in Nunavik that does not make inferences regarding food intake.
- Research that involves the collection and analysis of tissue samples from animals or plants, and not involving human research participants, is not covered within the scope of this Policy and does not require institutional REB review. However, funding program guidelines and licensing requirements in the North may impose obligations to engage communities. Community customs or codes of research practice may require securing regional and local permission, and reporting findings to communities (see NSERC literature on the Northern Research Program for professors and students/fellows, and Article 9.8).
- 7) Research that incidentally involves a small proportion of Aboriginal individuals but is not intended to single out, or describe, characteristics of Aboriginal people, for example, a study of the effectiveness of therapies to control high blood pressure in a sample of hospital outpatients, which is not designed to collect Aboriginal-specific data.
- Since Aboriginal participation is incidental rather than scheduled, community engagement is not required. If Aboriginal individuals self-identify during the collection of primary data, researchers should inquire

whether culturally appropriate assistance is desired to interpret, or support compliance with, the research project. However, it should be noted that including markers of Aboriginal identity in data collection may reveal anomalies that warrant further, more targeted research, which, if followed up, would require community engagement.

- 8) Research based on publicly available information as defined by this Policy, for example, historical, genealogical or analytic research based on public records, or data available or accessible in accordance with legislation.
  - Such research does not involve the collection of data from communities directly or from living persons and is not subject to REB review (see Article 2.2). Community engagement is not required. Findings of such research nevertheless may have an impact on the identity or heritage of persons or communities. In order to minimize any harm, researchers should seek culturally informed advice before use of such data to determine if harms may result and if other considerations such as sharing of the research results should be explored with the original source community (see Article 9.15).

## **Respect for First Nations, Inuit and Métis Governing Authorities**

**Article 9.3** Where a proposed research project is to be conducted on lands under the jurisdiction of a First Nations, Inuit or Métis authority, researchers shall seek the engagement of formal leaders of the community, except as provided under Articles 9.5, 9.6 and 9.7.

Research ethics review by the institutional REB and any responsible community body recognized by the First Nations, Inuit or Métis authority (see Articles 9.9 and 9.11) is required in advance of recruiting and securing consent of individuals.

**Application** Formal leaders with governance responsibilities on First Nations, Inuit or Métis land are charged with protecting the welfare of the community. Article 8.3(b) applies in such cases, requiring ethics review of research proposals by both “(i) the REB at the Canadian institution under the auspices of which the research is being conducted, and (ii) the REB or other responsible review body or bodies, if any, at the research site.” A local authority may approve research or delegate responsibility for reviewing research proposals to a local or regional body (e.g., the local health board or a body like the Mi’kmaq Ethics Watch).

Research involving multiple geographic communities raises complex issues of review and approval. Regional bodies or national organizations may facilitate research ethics review and make recommendations, but the decision to participate normally rests with the local communities.

Engagement with formal leadership is not a substitute for seeking consent from individual participants, as required by Chapter 3.

## Engagement with Organizations and Communities of Interest

**Article 9.4** For the purposes of community engagement and collaboration in research undertakings, researchers and REBs shall recognize Aboriginal organizations, including First Nations, Inuit and Métis representative bodies, and service organizations and communities of interest, as communities. They shall also recognize these groups through representation of their members on ethical review and oversight of projects, where appropriate.

**Application** Organizational communities and communities of interest may exist within the boundaries of territorial communities. Overlapping interests in these cases are considered in Articles 9.5 and 9.6. A majority of persons who self-identify as Aboriginal live in rural and urban communities outside of discrete First Nations, Métis or Inuit communities. Political organizations, friendship centres, housing associations, health access centres and other groups operating in rural or urban centres have been created to enhance the welfare of their own members or the populations that they serve. Organizations and communities of interest are potential partners in research on issues relevant to their communities, and are to be recognized as communities for the purposes of community engagement under this Policy.

An organization may participate in research focusing on its members (e.g., the board and staff of a friendship centre), or it may facilitate ethical engagement with the population that it serves (e.g., the clientele of a health access centre). A community of interest (e.g., Aboriginal youth who use an urban service program) may designate a local organization to provide advice and ethical protection for a project in which they participate.

Prospective participants may not necessarily recognize organizational communities or communities of interest as representing their interests. Where researchers and organizational communities or communities of interest collaborate in research (e.g., through a research agreement), prospective participants shall be informed about the extent of such collaboration (including how data will be shared) as part of the initial and ongoing consent process (see Article 3.2[i]).

## Complex Authority Structures

**Article 9.5** Where alternatives to securing the agreement of formal leadership are proposed for research on First Nations, Inuit or Métis lands or in organizational communities, researchers should engage community processes and document measures taken, to enable the REB to review the proposal with due consideration of complex community authority structures.

**Application** Researchers and REBs should not assume that approval of a project by formal leaders is the only avenue for endorsing a project. In some communities and some domains of knowledge, authority to permit and monitor research rests with knowledge keepers designated by custom rather than by election or appointment.

In First Nations settings, a confederacy council spanning several communities may be recognized as having authority over its members' traditional knowledge. In an Inuit community, the hamlet council, an Elders' circle, and a hunters and trappers organization may have overlapping responsibility and expertise with respect to the knowledge being sought. Métis Elders dedicated to conserving Michif language may assert their autonomy from political leaders, but choose to collaborate with educational or cultural agencies (see also Article 9.15).

The preferred course is to secure approval for research from both formal leaders of a community and customary authority. This is especially important for outsiders to communities, whose presence or intentions might be challenged as inappropriate. Researchers should engage community processes, including the guidance of moral authorities such as Elders, to avert potential conflict. These measures should be documented to assist the REB in considering the community engagement processes proposed (see Article 9.10). Where no agreement exists between formal community leadership and customary authority regarding the conduct of the proposed research, researchers should inform the REB. When alternative community engagement processes are followed to endorse a project, all other ethical safeguards set out in this chapter remain applicable.

### **Recognizing Diverse Interests within Communities**

**Article 9.6** In engaging territorial or organizational communities, researchers should ensure, to the extent possible, that they take into consideration the views of all relevant sectors – including individuals and subgroups who may not have a voice in the formal leadership. Groups or individuals whose circumstances make them vulnerable may need or desire special measures to ensure their safety in the context of a specific research project. Those who have been excluded from participation in the past may need special measures to ensure their inclusion in research.

**Application** Groups or individuals whose circumstances may make them vulnerable or marginalized within territorial or organizational communities should not be deprived of opportunities to participate in, and influence, research affecting their welfare. For example, people living with HIV/AIDS, impoverished youth or women who have suffered abuse may experience barriers to participation.

Gender-based analysis is being applied in First Nations, Inuit and Métis organizations and communities to promote or restore recognition of women's responsibilities in the conduct of community life – including decision making that directly affects their welfare. The legacy of patriarchal governance structures continues to pose challenges to women's full participation. Approaches that are attentive to cultural considerations help to ensure the equitable participation and benefit of women throughout the life cycle of a research project (see Article 4.2).

Research undertaken secretly or as a direct challenge to legitimate authority may increase risks to participants whose circumstances make them vulnerable, may deepen rifts within the community, and actually impede the advancement of social

justice. Strategies that have proven effective to secure the inclusion and promote the safety of diverse sectors within a community include: advocacy by moral authorities in the community; special measures to protect the identity of participants in small communities; identifying research questions that include rather than divide interest groups; or expanding the coverage of a project to multiple communities. In some cases, the risks to participants and communities involved with, or affected by, the proposed research outweigh the potential benefits likely to be gained, and the research should not be undertaken.

## **Critical Inquiry**

**Article 9.7** Research involving Aboriginal peoples that critically examines the conduct of public institutions, First Nations, Inuit and Métis governments, institutions or organizations or persons exercising authority over First Nations, Inuit or Métis individuals may be conducted ethically, notwithstanding the usual requirement of engaging community leaders.

**Application** Considerations in conducting critical inquiry are discussed more fully in Article 3.6. As in the case of research involving groups whose circumstances make them vulnerable, or communities of interest within an Aboriginal community (see Article 9.6), researchers undertaking critical inquiry research will need to adopt appropriate approaches to ensure that cultural norms are respected, that the safety of participants is protected, and that potential harms to the welfare of the larger community are minimized to the extent possible. Researchers may need to consult culturally relevant regional or national Aboriginal organizations for guidance.

For example, the Sisters in Spirit project of the Native Women’s Association of Canada (NWAC) that was launched in 2005 for a five-year period illustrates research of a national scope that incorporated a critical dimension. The project involved interviewing families of missing and murdered First Nations, Métis or Inuit women in urban and rural settings, and on First Nations territory. It examined, among other matters, the adequacy of public institutions and services, Aboriginal and non-Aboriginal, to protect the women’s well-being and support families in their efforts to deal with their losses. The objective was to effect policy change and improve the safety and well-being of Aboriginal women in Canada. NWAC has published its commitment to participatory research and the principles and practices that protect the privacy and well-being of participants. The project built on NWAC’s ongoing efforts to develop meaningful research relationships reflecting Aboriginal ways of knowing.

## **Respect for Community Customs and Codes of Practice**

**Article 9.8** Researchers have an obligation to become informed about, and to respect, the relevant customs and codes of research practice that apply in the particular community or communities affected by their research. Inconsistencies between community custom and this Policy should be identified and addressed in advance of initiating the research, or as they arise.

**Application** First Nations, Inuit and Métis codes of research practice derive from procedures and customs of predominantly oral cultures. While some rules may be in written form, their interpretation is dependent on experiential knowledge acquired through interactions in the community. An example is the strict limitation on making publicly available sacred knowledge that might be revealed within a trusting relationship. In academic culture, rules regarding limits on disclosure of information would reasonably be incorporated into a research proposal, and should be integrated into research agreements between communities and researchers where such exists.

The absence, or perceived absence, of a formal local research code or guidelines does not relieve the researcher of the obligation to seek community engagement in order to identify local customs and codes of research practice.

First Nation, Inuit and Métis customs and codes of behaviour distinguish among knowledge that can be publicly disclosed, disclosed to a specific audience, or disclosed under certain conditions. Determination of what information may be shared, and with whom, will depend on the culture of the community involved. Any restrictions on access to, or use of, traditional or sacred knowledge shared in the course of the research project should be addressed in the research agreement.

In Aboriginal communities, custom may restrict the observation, recording, or reporting of ceremonies or certain performances, and require approval of appropriate individuals. Article 10.3 addresses the requirement for ethics review of research involving observational studies, and associated ethical implications, which may include infringement on consent and privacy.

Many First Nations communities across Canada have adopted an ethics code originally developed to govern practice in the First Nations Regional Longitudinal Health Survey. The code asserts **o**wnership of, **c**ontrol of, **a**ccess to, and **p**ossession (OCAP) of research processes affecting participant communities, and the resulting data. OCAP addresses issues of privacy, intellectual property, data custody and secondary use of data, which are also covered later in this chapter.

Inuit communities and organizations are considering addressing similar concerns, including adoption or adaptation of OCAP. For example, possession agreements, which are distinct from research agreements, are set out in a memorandum of understanding between the institution of the researcher and the community (usually represented by the land claim organization). The possession agreement covers the control and use of data and human biological materials collected over the course of the research. The agreement may continue to exist long after the research is completed, to allow control and use of data and human biological materials for Inuit-initiated research.

Researchers should consult their own institutions to ensure that the application of OCAP or other community-based ethics codes is consistent with institutional

policies. Where divergences exist, they should be addressed and resolved prior to the commencement of the research, or as they arise over the course of the research.

First Nations, Inuit and Métis scholars attached to academic institutions as faculty members, students or research associates are increasingly engaged in research involving their own communities, and sometimes their own family members. They are generally exempt from restrictions on physical access to territory or personal access to community members. However, as members of institutions that adhere to this Policy, they are subject to the ethical duty to respect community customs and codes of research practice when conducting research in their own local or cultural communities, and to engage the relevant community as required by this Policy. In these cases, institutional REBs may be concerned about researchers being in a conflict of interest and should manage the conflict of interest in accordance with Articles 7.2 and 7.4.

Life history and language research are examples of research areas where insider relationships and cultural competencies provide unique opportunities to extend the boundaries of knowledge. Although it can be argued that recording the life history of an elderly relative is a family matter rather than a community matter, when undertaken as research, community engagement is important to ensure that the following considerations are reviewed: the potential impact of such research on the wider community; conflicts between the individualist norms of the academic environment and the norms of the community; and the possibility of unclear or mistaken assumptions on the part of participant and researcher. During the consent process, researchers should give the participant the opportunity to identify the relevant form of community engagement, and at what stage such engagement should occur. This may include engaging with extended family members, peers of the participant with whom the researcher's interpretations can be validated, or Elders knowledgeable about cultural rules governing disclosure of privileged information.

### **Institutional Research Ethics Review Required**

**Article 9.9** Research ethics review by community REBs or other responsible bodies at the research site will not be a substitute for research ethics review by institutional REBs, and will not exempt researchers affiliated with an institution from seeking REB approval at their institution, subject to Article 8.1. Prospective research and secondary use of data and human biological materials for research purposes is subject to research ethics review.

**Application** Applying this Policy in a way that accommodates the diversity of First Nations, Inuit and Métis cultures, and mixed Aboriginal communities in urban centres is complex. For example, the fit between institutional policies and community customs and codes of research practice may be unclear, requiring researchers to adapt conventional practice or negotiate a resolution.

Consistent with Article 8.3(b), research conducted outside the jurisdiction of the researcher’s institution shall undergo prior research ethics review by both “(i) the REB at the Canadian institution under the auspices of which the research is being conducted, and (ii) the REB or other responsible review body or bodies, if any, at the research site.”

Article 8.1 permits review models for multi-site research that do not require separate research ethics review by each site involved in a research project. In cases where the community is the direct recipient of funding and has constituted a local REB that is party to an agreement with the researcher’s institution, review by the institution’s REB may not be required.

In accordance with Article 8.4, communication between the institutional REB and the responsible agency in the community may assist in resolving inconsistencies between institutional policy and community customs and codes of research practice. Where a community research ethics review is required in addition to the mandatory institutional REB review, reconciling differences may require resubmission to one or both review bodies.

Researchers and REBs should recognize that research ethics review by community bodies will often pursue purposes and apply criteria that differ from the provisions of this Policy. The express purpose of most Aboriginal community codes of research practice is to ensure the relevance of research undertakings to community needs and priorities, and respect for First Nations, Inuit and Métis identities, cultures and knowledge systems. While community codes of practice and research agreements typically share many of the goals of institutional policies, the approaches to achieving those goals may differ significantly. It is therefore inappropriate to insist on uniformity between community practices and institutional policies. For example, when researchers seek to interview Elders willing to share their knowledge according to traditional customs of consent, REBs should not impose language and processes that may be experienced as culturally inappropriate or awkward (see Article 3.12).

In cases where REB review of research on topics related to Aboriginal peoples or affecting Aboriginal communities is regularly required, the REB membership should be modified to ensure that relevant and competent knowledge and expertise in Aboriginal cultures are available within its regular complement. Aboriginal scholars or members drawn from First Nations, Inuit or Métis communities may fill this role (see Article 6.4). For occasional review of Aboriginal research that is likely to affect the welfare of a community or communities, consultation with ad hoc advisors or delegation to a specialized or multi-institutional REB may be appropriate (see Articles 6.5 and Article 8.1).

The membership of community review bodies of First Nations, Inuit or Métis communities will not necessarily duplicate the membership criteria set out in this Policy. In the context of scarce resources in community organizations, the same



personnel may be involved in reviewing the ethics of a proposal and co-managing the research project. An expectation that conflicts of interest will be managed by separating research ethics review and project management functions may impose unsupportable demands on small communities. In these circumstances, researchers and participating Aboriginal communities should address the ethical safeguards of the community and its members that can be best achieved in circumstances when multiple roles are assumed by the same person (see Chapter 7 and, in particular, Article 7.2).

### **Requirement to Advise the REB on a Plan for Community Engagement**

**Article 9.10** When proposing research expected to involve First Nations, Inuit or Métis participants, researchers shall advise their REB how they have engaged, or intend to engage, the relevant community. Alternatively, researchers may seek REB approval for an exception to the requirement for community engagement, on the basis of an acceptable rationale.

**Application** In order for REBs to consider whether the form of community engagement chosen by the researcher is appropriate, they will require evidence in the form of one or more of the following: (a) a preliminary or formal research agreement between the researcher and the responsible body at the research site; (b) a written decision or documentation of an oral decision taken in a group setting to approve the proposed research or to decline further participation; and (c) a written summary of advice received from a culturally informed advisory group or ad hoc committee (e.g., an urban community of interest). Where community engagement is not being proposed, perhaps due to the nature of the research and the community context (see Articles 9.1 and 9.2), researchers shall provide a rationale acceptable to the REB.

Provision of a research agreement is particularly emphasized in health research funded by CIHR (see CIHR *Guidelines for Health Research Involving Aboriginal People* in References at end of this chapter).

Where a researcher has an ongoing relationship with a community, a letter from formal or customary leaders in the relevant community may signal approval, and suffice to proceed with the research.

Where, under the provisions of Articles 6.11 and 10.1, a community signals during preliminary discussions with researchers, prior to REB review, that the research may proceed but that it does not want further community engagement, researchers shall document and present to the REB the steps they took to invite and facilitate engagement by the community. See Article 9.14 on how researchers may assist in capacity building.

Although researchers shall offer the option of engagement, a community may choose to engage nominally or not at all, despite being willing to allow the research to proceed. A community may, for example, support a research project carried out

independent of community influence, or without any further collaboration of the community in the actual implementation of the research in order to use scientifically defensible results to validate a negotiating position.

## Research Agreements

**Article 9.11** Where a community has formally engaged with a researcher or research team through a designated representative, the terms and undertakings of both the researcher and the community should be set out in a research agreement before participants are recruited.

**Application** Research agreements serve as a primary means of clarifying and confirming mutual expectations and, where appropriate, commitments between researchers and communities. Research agreements, where applicable, shall precede recruitment of individual participants and collection of, or access to, research data. The scope of the agreement will depend on the level of engagement which the community desires, and the availability of resources to support community participation.

At a minimum, the agreement should address the ethical protections that would apply to securing individual consent for a comparable project, and should specify any commitments regarding collective community participation and decision making, sharing of benefits and review, and updating of the agreement. Expanding on information normally provided to an individual participant (see Article 3.2), agreements typically set out the purpose of the research and detail mutual responsibilities in project design, data collection and management (see Article 5.3); analysis and interpretation; credit due to knowledge holders; protection (and non-disclosure) of restricted knowledge; sharing of benefits or royalties flowing from intellectual property where applicable; production of reports; co-authorship; dissemination of results; and a conflict resolution process. Provisions for any anticipated secondary use of the information or human biological material, and associated data collected, should also be addressed at that time, and documented in the research agreement (see Article 9.20).

Where a community has adopted or adheres to a code of research practice, the agreement may set out responsibilities in accordance with that code and the specific requirements of the research project. In less formal circumstances, the agreement may be relatively brief, and subject to clarification as the project unfolds. The CIHR *Guidelines for Health Research Involving Aboriginal People* (2007) provide examples of elements that may be included in research agreements (see References at the end of this chapter).

Research agreements are increasingly being recognized by academic institutions (and the researchers associated with them) as providing reference points for research ethics review process and approval on such elements as consent, confidentiality, and access to and use of information. Agreements that specify procedures for community research ethics review, included as part of the institutional ethics

application, can provide contextual information and guidance for REBs conducting initial review of applications, and continuing research ethics review throughout the project. Researchers should check with their institutions regarding signing authority for research agreements (see Article 9.18).

Building relationships, clarifying the goals of a project, and negotiating agreements requires substantial investment of time and resources on the part of the community and the researcher. Development and participation costs incurred by the community and the researcher should be factored into proposals to the extent possible within funding guidelines.

Community agreement that a research project may proceed is not a substitute for securing the consent of individuals recruited to participate in that project, in accordance with Chapter 3. Consent of prospective participants shall precede collection of, or access to, data or human biological materials. Consistent with the provisions of Article 3.12, if signed written consent is not culturally appropriate, the researcher shall inform the REB of alternative processes employed for seeking and documenting consent.

Consent shall be given in accordance with the research agreement where one exists. Where research agreements provide that community partners will have limited or full access to identifiable personal data, the consent of participants to this disclosure shall form part of the consent process. Access to confidential information provided by an individual is subject to privacy law.

Researchers should be aware of the first language of Aboriginal participants and, if an Aboriginal language, researchers should make available translation by a knowledgeable person during the consent process, and during the conduct of research in accordance with the wishes of the participant (see Article 4.1). Researchers should be aware of the official status of Inuit languages in Inuit regions.

## **Collaborative Research**

**Article 9.12** As part of the community engagement process, researchers and communities should consider applying a collaborative and participatory approach as appropriate to the nature of the research, and the level of ongoing engagement desired by the community.

**Application** While community engagement is appropriate in any research that affects Aboriginal communities, the nature and degree of collaboration between the researcher and the community will depend on the nature of the research, and the community context. Collaborative approaches in research with Aboriginal communities are a means of facilitating mutually respectful and productive relations (see Article 9.2).

Collaborative research is generally understood to involve respectful relationships among colleagues, each bringing distinct expertise to a project. Collaboration often involves one or another of the partners taking primary responsibility for certain

aspects of the research, such as addressing sensitive issues in community relations, or scientific analysis and interpretation of data.

In general, community-based research takes place at community sites. Some forms of research are community-centred in that the research focuses not only on individuals but on the community itself, and may become a project conducted by, for and with the community.

Participatory research is a systematic inquiry that includes the active involvement of those who are the subject of the research. Participatory research is usually action-oriented, where those involved in the research process collaborate to define the research project, collect and analyze the data, produce a final product and act on the results. It is based on respect, relevance, reciprocity and mutual responsibility.

Where participatory research is adopted, the terms and conditions should be set out in a research agreement (see Article 9.11).

### **Mutual Benefits in Research**

**Article 9.13** Where the form of community engagement and the nature of the research make it possible, research should be relevant to community needs and priorities. The research should benefit the participating community (e.g., training, local hiring, recognition of contributors, return of results), as well as extend the boundaries of knowledge.

**Application** To benefit the participating community, a research project should be relevant to community priorities and have the potential to produce valued outcomes from the perspective of the community and its members.

Relevance and community benefit can take a number of forms depending on the type of research being conducted, and the forms of community engagement. For example, genetic research on diabetes in a First Nations community is unlikely to benefit the community in the short term, but collaboration may facilitate increased knowledge of the condition, and what changes can be made to improve health outcomes. Collaborative research can thus accommodate basic, as well as applied, research, and include short-term and long-term benefits. In another example, a community invites a researcher to collaborate in a research project about housing and homelessness in an Inuit community. Using participatory research methods and social science tools, the nature, extent and consequences of the local housing shortage are documented, enabling the community to effectively communicate its needs to non-Inuit (*Qallunaat*) authorities. Other benefits include training workshops that provide employment and transfer skills to Inuit youth involved in data collection, field experience in community-based research for university student assistants and materials useful to other Inuit communities in subsequent research.

Collaborative research approaches provide the community with the opportunity to discuss risks and potential benefits, and to minimize risks. Where participatory

research is undertaken, the research report might also formulate recommendations on how to implement interventions resulting from the research for the benefit of the participating community.

A possible outcome of collaborative research, and in particular participatory research, is increased capacity to carry out research that can more readily be conducted in Aboriginal languages and oral modes. The exploration, articulation and application of knowledge specific to a community or communities are thus advanced, potentially benefiting other First Nations, Inuit or Métis communities through knowledge transfer.

Researchers should provide communities access to research data that will allow them to address pressing issues through community-generated policies, programs, and services (see Article 9.8 and the Application of Article 9.11). Territorial and organizational communities and communities of interest may also seek to share in the benefits of research activities, which may include direct research grants, release time for project personnel, overhead levies on shared projects and commercialization of research discoveries.

### **Strengthening Research Capacity**

**Article 9.14** Research projects should support capacity building through enhancement of the skills of community personnel in research methods, project management, and ethical review and oversight.

**Application** Collaborative research approaches provide for reciprocal learning and for transfer of skills and knowledge between the community and the researcher. Researchers should foster education and training of community members to enhance their participation in research projects. Employing Aboriginal research assistants and translators is already common practice in community-based projects. Extending skills transfer through a program of training will support collaboration with institutions, and advance the capacity of communities to initiate and implement their own research. Collaborative research can also support building capacity of the research community to conduct culturally relevant research.

Lack of engagement by communities may be due to inadequate financial or human resources. Communities vary widely in the level of human and material resources they have available to collaborate with research initiatives. Structural barriers may prevent access to, and participation in, research. For example, small, remote communities and many urban communities of interest have limited organizational resources to advise or collaborate in research. The least organizationally developed communities are the most vulnerable to exploitation. Research undertaken in these circumstances should strive to enhance capacity for participation.

Funding programs that target the development of Aboriginal research and capacity building seek to generate significant research training opportunities. Funding criteria allow researchers to include in their grant applications stipends for

undergraduate, master's or doctoral students, or post-doctoral researchers, as appropriate, with priority given to Aboriginal candidates. The time required to establish collaborative relationships may be difficult to accommodate in the programs of students. Mentorship by experienced researchers who introduce students to communities and monitor their ethical practice can facilitate the trust-building process and advance student progress.

### **Recognition of the Role of Elders and Other Knowledge Holders**

**Article 9.15** Researchers should engage the community in identifying Elders or other recognized knowledge holders to participate in the design and execution of research, and the interpretation of findings in the context of cultural norms and traditional knowledge. Community advice should also be sought to determine appropriate recognition for the unique advisory role fulfilled by these persons.

**Application** Within First Nations, Inuit and Métis communities, persons with special gifts carry varied roles and responsibilities in conserving and transmitting traditional knowledge and expressions of culture. They often are fluent in their traditional language. They model respectful relationships and may conduct ceremonies, pass on oral history, and offer guidance in community affairs. Their gifts are normally refined over a lifetime. Thus, Elders who have followed a rigorous path of learning over a long period are highly respected. Younger persons may also gain recognition as gifted knowledge holders.

High regard by the community that knows the Elder or other knowledge holder is the most reliable indicator of an individual's authority. Each community or nation has particular ways of approaching Elders or knowledge holders respectfully. In many First Nations this involves the presentation and acceptance of tobacco to symbolize entering into a relationship. In some communities, feasting or gift-giving is appropriate.

Elders are now being recognized in research proposals and grant applications as providers of access to community networks, ethical guidance to researchers, and advice in interpreting findings in the context of traditional knowledge (see Article 9.17). Researchers should seek advice from the community and the Elders regarding the appropriate recognition of the contribution of Elders and knowledge holders, which may include providing honoraria, acknowledging contributions by name or, as directed, withholding the Elder's identity in reports and publications.

### **Privacy and Confidentiality**

**Article 9.16** Researchers and community partners shall address privacy and confidentiality for communities and individuals early on in the community engagement process. The extent to which limited or full disclosure of personal information related to the research is to be disclosed to community partners shall be addressed in research

agreements where these exist. Researchers shall not disclose personal information to community partners without the participant’s consent, as set out in Article 3.2(i).

**Application** Researchers and community partners should consider early in the design of the research how community codes of research practice fit with provisions for privacy and confidentiality as set out in Chapter 5. Where inconsistencies exist, they should be resolved in advance of starting the research. The research agreement should address how inconsistencies will be addressed if they arise over the course of the conduct of the research project.

In First Nations communities, privacy and confidentiality of identifiable personal and community information may be affected by the application of the principles of ownership, control, access and possession (OCAP – see definition in Application of Article 9.8). The First Nations Regional Longitudinal Health Survey administered by regional First Nations organizations has addressed balancing confidentiality and access by having communities designate a regional organization to hold data, while local authorities make decisions on who can access the data, and under what conditions. In practice, the organization that serves as data steward evaluates requests for information, and its recommendations to community authorities have considerable influence.

Whatever the nature of the research, it shall be designed to include safeguards for participant privacy and measures to protect the confidentiality of any data collected. Small Aboriginal communities are characterized by dense networks of relationships. As a result, coding individual data is often not sufficient to mask identities, even when data are aggregated. Some Aboriginal participants are reluctant to speak to interviewers from their own community because of privacy concerns. Communities themselves have distinguishing characteristics, which in some cases have compromised efforts to disguise the research site, and has led to the stigmatization of entire communities.

On the other hand, in some social sciences and humanities research, the significance of information is tied to the identity of the source. In these cases individual attribution, with consent, is appropriate. When individual participants waive anonymity, researchers should ensure that this is documented (see Application of Article 5.1 and Article 9.11). Communities partnering in research may wish to be acknowledged (e.g., in the research report) for their contribution to the research effort.

Research undertaken with participants who have suffered traumatic experiences (e.g., former residential school students) poses a risk of re-traumatizing participants. Researchers should anticipate such risks in the research design, and adhere to cultural protocols for determining participant needs and access to trauma counselling.

Privacy protections in research are evolving. Respect for, and accommodation of, First Nations, Inuit and Métis priorities on joint ownership of the products of research and maintaining access to data for community use should guide research practices – with appropriate deference to applicable federal, provincial and territorial privacy legislation.

### **Interpretation and Dissemination of Research Results**

**Article 9.17** Researchers should afford community representatives engaged in collaborative research an opportunity to participate in the interpretation of the data and the review of research findings before the completion of the final report, and before finalizing all relevant publications resulting from the research.

**Application** Where collaborative approaches are followed, researchers should ensure continuing communications with the participating community. Territorial or organizational communities or communities of interest engaged in collaborative research may consider that their review and approval of reports and academic publications is essential to validate findings, correct any cultural inaccuracies, and maintain respect for community knowledge (which may entail limitations on its disclosure). Researchers should integrate suggestions from the community representatives in the publication. If disagreement about interpretation arises between researchers and the community and it cannot be resolved, researchers should either (a) provide the community with an opportunity to make its views known, or (b) accurately report any disagreement about the interpretation of the data in their reports or publications. This should not be construed as giving the community the right to block the publication of findings. Rather, it gives the community the opportunity to contextualize the findings.

Final reports shall be made available to the territorial or organizational community or community of interest participating in the research. Researchers and communities should clarify the extent to which research findings will require translation, plain language summaries or oral presentations to community members, in order to make the research findings accessible to the community.

An Aboriginal community, and those who participated in the research, should have the option to participate in deciding how collective or individual contributions to the research project will be acknowledged and credited in the dissemination of results (e.g., acknowledgement of co-authorship in research reports or at conferences and seminars).

### **Intellectual Property Related to Research**

**Article 9.18** In collaborative research, intellectual property rights should be discussed by researchers, communities and institutions. The assignment of rights, or the grant of licences and interests in material that may flow from the research, should be specified in a research agreement (as appropriate) before the research is conducted.



**Application** Researchers, communities and institutions should be aware that all knowledge and information is not necessarily protected under the existing law. Existing intellectual property legislation generally protects works and inventions. Strict criteria are used to define intellectual property rights. Understanding and communicating what qualifies, or does not qualify, as intellectual property for the purposes of research under this Policy is a joint responsibility of communities, researchers and institutions.

When undertaking research guided by community engagement, researchers, institutions and communities may need to first address issues regarding access to data, and the use of data for the purpose of the research or in the dissemination of research findings. Regarding access to and use of data, a research agreement may set out any limits on the disclosure of personal or privileged information (subject to applicable legal and regulatory requirements and the guidance in Chapter 5 of this Policy). It might include provisions to review reports and publications regarding the research prior to publication, or limits on the release of, or access to, research results (subject to applicable laws). Provisions for any anticipated secondary use of the information or human biological material, and associated data collected, should also be addressed and documented in this agreement. It may also set out any interests, licences or assignments in copyright flowing from publications about, or based on, the research (see Articles 9.8, 9.11 and 9.16).

Some knowledge collected as a result of the research may have commercial applications, and lead to the development of marketable products. With respect to commercialization of results of collaborative research, researchers and communities should discuss and agree on the use, assignment or licensing of any intellectual property (e.g., any patents or copyright), resulting from the marketable product, and document mutual understandings in an agreement. If the proposed research has explicit commercial objectives, or direct or indirect links to the commercial sector, researchers and communities may want to include provisions related to anticipated commercial use in research agreements. These provisions should be clearly communicated to all parties in advance, consistent with the consent process.

Researchers should consult the research office of their institution before entering into a research agreement that includes intellectual property provisions. Researchers should also consult the program literature or policies on intellectual property and copyright adopted by the federal research agencies CIHR, NSERC and SSHRC (available on their websites), and seek legal advice where appropriate.

### **Collection of Human Biological Materials Involving Aboriginal Peoples**

**Article 9.19** As part of community engagement, researchers shall address and specify in the research agreement the rights and proprietary interests of individuals and communities, to the extent such exist, in human biological materials and associated data to be collected, stored and used in the course of the research.

**Application** Canadian law does not provide clear recognition of property rights in human biological materials. Researchers should be aware, however, that Aboriginal people and communities may seek to maintain control over, and access to, data and human biological materials collected for research. This is in accordance with Aboriginal world views about “full embodiment,” in which every part and product of the human body is sacred and cannot be alienated. Consistent with Articles 9.8 and 9.11 and Chapter 12, researchers and communities should address and specify in the research agreement:

- the objectives for collection, use and storage of human biological materials;
- the roles and responsibilities regarding custodianship of the data and the human biological materials; and
- any future use of these human biological materials and associated data, including material transfer agreements to third parties, and any subsequent requirements for community engagement.

Researchers must seek consent, in accordance with Articles 12.1 and 12.2, from individuals who are invited to donate their biological materials.

### **Secondary Use of Information or Human Biological Materials Identifiable as Originating from Aboriginal Communities or Peoples**

Ongoing sensitivity about secondary use of data collected for approved purposes arises from experiences with misrepresentation of Aboriginal peoples; use of data or human biological materials without appropriate engagement with the source community or consent of participants; and lack of reporting to communities on research outcomes. For example, members of Nuu-chah-nulth communities in British Columbia provided blood samples for research on rheumatic disease. They vigorously protested the use of their blood components for subsequent unauthorized genetic research. In addition, there are fears in First Nations communities that access to health data for purposes other than treatment will facilitate unauthorized government surveillance.

When seeking to undertake research involving secondary use of data identifiable as originating from a specific Aboriginal community or segment of the Aboriginal community at large, researchers shall, through community engagement as appropriate, address any potential inadvertent identification of communities, or misuse of traditional knowledge. Requirements regarding the participant’s consent for secondary use of identifiable information are addressed in Articles 9.20 and 9.21.

**Article 9.20** Secondary use of data and human biological material identifiable as originating from an Aboriginal community or peoples is subject to REB review.

Researchers shall engage the community from which the data or human biological materials and associated identifiable information originate, prior to initiating secondary use where:

- (a) secondary use has not been addressed in a research agreement and has not been authorized by the participants in their original individual consent; or
- (b) there is no research agreement; and
- (c) the data are not publicly available or legally accessible.

Individual consent for the secondary use of identifiable information is required unless the REB agrees that either Articles 5.5 or 5.6, or Articles 12.3 or 12.4 may apply.

**Application** Where the researcher can satisfy the REB that secondary use is consistent with an existing research agreement, the REB may require that the researcher engage the community from which the data or human biological materials and associated identifiable information originate – in accordance with the terms of the research agreement. New consent from individuals for secondary use is not required where the proposed secondary use is authorized by the REB in accordance with this Policy.

**Article 9.21** Where research relies only on publicly available information, or on legally accessible information as defined in Article 2.2, community engagement is not required. Where the information can be identified as originating from a specific community or a segment of the Aboriginal community at large, seeking culturally informed advice may assist in identifying risks and potential benefits for the source community.

**Application** Research based only on publicly available information or legally accessible information as defined by this Policy, does not involve the collection of data from communities directly, or from living persons. As indicated in Chapter 2, REB review for this type of research is not required. Community engagement is not required. Examples are historical or genealogical research or statistical analysis.

In these cases, researchers may not have any direct relationship with communities but their findings may, nevertheless, have an impact on the identity or heritage of persons or communities. In order to minimize any harm, researchers should seek culturally informed advice before the use of such data to determine if harms may result and if other considerations, such as sharing of the research results, should be explored with the original source community (see Article 9.15).

Where access to publicly available information or legally accessible information leads to new research initiatives to collect additional information from identified communities or individuals, REB review is required. The provisions set out in Article 5.6 apply for new initiatives of this kind.

**Article 9.22** REB review is required where the researcher seeks data linkage of two or more anonymous datasets or data associated with human biological materials and there

is a reasonable prospect that this could generate information identifiable as originating from a specific Aboriginal community or a segment of the Aboriginal community at large.

**Application** The REB may determine that community engagement is required to seek guidance on secondary use. Articles 5.5 and 5.6 or Articles 12.3 and 12.4 may apply.

Consistent with Article 2.4, REB review is not required for research involving only anonymous datasets or anonymous human biological materials, and associated data, that cannot be identified as originating from a specific Aboriginal community or a segment of the Aboriginal community at large. Community engagement is not possible given that the data or human biological materials cannot be linked to a specific Aboriginal community or specific individuals. Where the researcher seeks data linkage of two or more anonymous sets of information or human biological materials and there is a reasonable prospect that this could generate identifiable information, then REB review is required.

## Endnotes

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<sup>1</sup> Indian peoples commonly identify themselves as “First Nations.” First Nation: A term that came into common usage in the 1970s to replace the word “Indian,” which some people found offensive. Although the term First Nation is widely used, no legal definition of it exists. Among its uses, the term “First Nations peoples” refers to the Indian peoples in Canada, both Status and non-Status. Some Indian peoples have also adopted the term “First Nation” to replace the word “band” in the name of their community. See Indian and Northern Affairs Canada, Terminology, available at [www.ainc-inac.gc.ca/ap/tln-eng.asp](http://www.ainc-inac.gc.ca/ap/tln-eng.asp).

<sup>2</sup> [www.nserc-crsng.gc.ca/NSERC-CRSNG/Policies-Politiques/MOURoles-ProtocolRoles/index\\_eng.asp](http://www.nserc-crsng.gc.ca/NSERC-CRSNG/Policies-Politiques/MOURoles-ProtocolRoles/index_eng.asp)

<sup>3</sup> Constitution Act, 1982, s. 35. [http://laws.justice.gc.ca/en/const/9.html#anchors:7-bo-ga:l\\_II](http://laws.justice.gc.ca/en/const/9.html#anchors:7-bo-ga:l_II)

<sup>4</sup> [www.wipce2008.com/enews/pdf/wipce\\_fact\\_sheet\\_21-10-07.pdf](http://www.wipce2008.com/enews/pdf/wipce_fact_sheet_21-10-07.pdf)

## References

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- Canadian Institutes of Health Research. *CIHR Guidelines for Health Research Involving Aboriginal People*. May 2007. [www.cihr-irsc.gc.ca/e/29134.html](http://www.cihr-irsc.gc.ca/e/29134.html)
- ———. *CIHR Best Practices for Protecting Privacy in Health Research*. September 2005. [www.cihr-irsc.gc.ca/e/29072.html](http://www.cihr-irsc.gc.ca/e/29072.html)
- First Nations Centre. *OCAP: Ownership, Control, Access and Possession*. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization [www.naho.ca/english/pub\\_research.php](http://www.naho.ca/english/pub_research.php)
- First Nations Regional Longitudinal Health Survey (RHS). [www.rhs-ers.ca/english](http://www.rhs-ers.ca/english)

- Interagency Advisory Panel on Research Ethics. Aboriginal Research Ethics Initiative. “Issues and Options for Revisions to the *Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans* (TCPS): Section 6: Research Involving Aboriginal Peoples.” February 2008. [www.pre.ethics.gc.ca/eng/archives/policy-politique/reports-rapports/riap-rapa/](http://www.pre.ethics.gc.ca/eng/archives/policy-politique/reports-rapports/riap-rapa/)
- Inuit Tapiriit Kanatami (ITK) and Nunavut Research Institute (NRI). *Negotiating Research Relationships with Inuit Communities: A Guide for Researchers*. Edited by Scot Nickels, Jamal Shirley and Gita Laidler. ITK and NRI: Ottawa and Iqaluit. [www.itk.ca/publications/negotiating-research-relationships-inuit-communities-guide-researchers](http://www.itk.ca/publications/negotiating-research-relationships-inuit-communities-guide-researchers)
- *Nipingit*. National Inuit Committee on Ethics and Research, a joint program of the Inuit Tuttarvingat the National Aboriginal Health Organization and Inuit Tapiriit Kanatami, *Research and Research Ethics Fact Sheets*. [www.naho.ca/inuit/e/ethics/factsheets.php](http://www.naho.ca/inuit/e/ethics/factsheets.php)
- Royal Commission on Aboriginal Peoples. *Report of the Royal Commission on Aboriginal Peoples*. “Ethical Guidelines for Research.” In *Volume 5, Renewal: A Twenty-Year Commitment*, Ottawa: Canada Communications Group. 1996. It can also be accessed at [www.ainc-inac.gc.ca/ap/rrc-eng.asp](http://www.ainc-inac.gc.ca/ap/rrc-eng.asp)
- United Nations Educational, Scientific and Cultural Organization. *Universal Declaration on Bioethics and Human Rights*. Adopted October 19, 2005, by the 33<sup>rd</sup> session of the General Conference of UNESCO. 2005. <http://unesdoc.unesco.org/images/0014/001461/146180e.pdf>
- United Nations. Convention on Biological Diversity. 1992. [www.cbd.int/convention/convention.shtml](http://www.cbd.int/convention/convention.shtml)