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## Policy Writing as Dialogue: Drafting an Aboriginal Chapter for Canada's Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

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# Policy Writing as Dialogue: Drafting an Aboriginal Chapter for Canada's Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

## **Abstract**

Writing policy that applies to First Nations, Inuit and Métis peoples in Canada has become more interactive as communities and their representative organizations press for practical recognition of an Aboriginal right of self-determination. When the policy in development is aimed at supporting “respect for human dignity” as it is in the case of ethics of research involving humans, the necessity of engaging the affected population becomes central to the undertaking.

## **Keywords**

First Nations, Inuit, Métis, research involving humans, Tri-Council Policy, health research, ethical research, policy

## **Acknowledgments**

Views expressed in this article are those of the authors and do not represent positions of the Interagency Advisory Panel and Secretariat on Research Ethics, the Institute of Aboriginal Peoples' Health or CIHR, NSERC or SSHRC.

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## Introduction

Writing policy that applies to First Nations, Inuit and Métis peoples in Canada has become more interactive as communities and their representative organizations press for practical recognition of an Aboriginal right of self-determination. When the policy in development is aimed at supporting “respect for human dignity” as it is in the case of ethics of research involving humans, the necessity of engaging the affected population becomes central to the undertaking.

The authors of this article have carried leadership responsibilities over the past several years in parallel processes leading to revision of Canada’s *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS). The TCPS, issued in 1998, is the common policy of Canadian Institutes of Health Research (CIHR), Social Sciences and Humanities Research Council (SSHRC) and Natural Sciences and Engineering Research Council (NSERC), the agencies responsible for distributing research funding allocated by the Government of Canada. To be eligible to receive research funds, institutions or organizations and the researchers affiliated with them are required to adhere to any of the Agencies’ policies, including the TCPS.

Marlene Castellano chairs the Aboriginal Research Ethics Initiative of the Inter-agency Advisory Panel on Research Ethics (PRE). PRE was established in 2001 by the presidents of the three federally-supported research councils to recommend revisions to the TCPS in response to evolving ethics issues. Jeff Reading is the former Scientific Director of the Institute of Aboriginal Peoples’ Health (IAPH), one of thirteen CIHR institutes. IAPH, established in 2000, set an early priority on developing ethical guidelines for researchers engaged in health research involving First Nations, Inuit, and Métis people and communities.

The parallel initiatives of PRE and CIHR-IAPH have come to fruition. CIHR adopted *Guidelines for Health Research Involving Aboriginal People* in 2007 (Canadian Institutes of Health Research, 2007). PRE released a first draft of revisions to the TCPS in 2008, including a new chapter on Aboriginal research, which is currently undergoing revision (Interagency Panel on Research Ethics, 2008). This article reflects on the process of developing policy on research ethics from the perspective of authors of First Nation origin who are committed to enhancing the agency of Aboriginal peoples in processes that affect them.

### **Ethical Relations and Ethics Policy**

Elders in Aboriginal societies across Canada speak of the responsibility of humans to maintain a balanced relationship with all the beings, human and non-human, with whom they share life on Mother Earth. Languages of ancient origin convey the importance of principles such as “miyowicehtowin”, having good relations in western Cree culture, and “Skennen kowa”, Great Peace in Iroquois culture, valuing relationships that go beyond resolving conflicts to actively care for one another’s welfare. An Anishnabe Elder speaking to the Royal Commission on Aboriginal Peoples spoke of the ethical imperatives in his traditional culture:

At the beginning of time the Creator gave [Indians] law to follow. He gave the four directions. He gave them sweetgrass, the tree, the animal and the rock. The sweetgrass represents kindness; the tree represents honesty; the animal, sharing; and the rock is strength. (RCAP. 1996a: 654)

The introduction of colonial policies imposed rules that frequently violated the traditional value of maintaining respectful, mutually beneficial relations. Policy, to Aboriginal people has come to mean constraints of foreign origin. Research has taken on similar negative associations, as inquiry conducted by outsiders, harvesting information that is translated into distorted

representations of the people's experience, and policies that limit the arena for self-determined action.

The first task of ethics policy development was to bridge conceptual worlds, not repeating errors of the past by assuming that Aboriginal peoples needed instruction in ethics but, rather, connecting with those deep currents of ethical sensibility that live on in contemporary community life. The approach taken was to foster dialogue among First Nation, Inuit, and Métis communities interested or engaged in research, organizations representing key sectors of the Aboriginal community, the broader research community in Canada, CIHR-IAPH, and PRE in an iterative process of policy formation.

### **Converging Streams of Development**

Scientific breakthroughs often demonstrate that convergent insights can appear independently in different places. Innovators declare: "There is nothing so powerful as an idea whose time has come." Initiatives to develop ethics policy had the benefit of a movement that was gathering momentum in the Aboriginal community, in the research councils, and in international venues.

In 1992, Canada's Royal Commission on Aboriginal Peoples (RCAP) launched consultations on a comprehensive program of research. The response at a workshop convened to engage Aboriginal researchers was the cry: "We've been researched to death!" An Elder in the workshop intervened with the proposition: "If it's true that we have been researched to death, maybe it's time we started researching ourselves back to life" (Oral Communication, 1992).

In the years since that meeting, the words "researching ourselves to life" have become a familiar affirmation of the value of research and the possibility of Aboriginal ownership of the processes and outcomes of research. Numerous studies sponsored by RCAP were conducted by

Aboriginal and non-Aboriginal scholars and community researchers, often in collaboration with communities. Researchers were bound by RCAP's "Ethical Guidelines for Research" (RCAP, 1996b:325-328), which were articulated by a subcommittee made up of Aboriginal persons with extensive research experience. RCAP research gave substance to the expectation that knowledge creation could be owned once again by Aboriginal people.

In 1998 the First Nations and Inuit Regional Health Survey (<http://www.rhs-ers.ca/english/>) was launched in partnership between regional First Nations and Inuit organizations and Health Canada. Despite the tensions that arose in executing the first RHS, the results were sufficiently positive that the First Nations component has been repeated in further cycles, 2002 and 2007. The First Nations oversight committee for the RHS developed a statement on the conduct of research which was later encapsulated in a position paper "Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research" published on-line by the First Nations Centre of the National Aboriginal Health Organization (NAHO, 2007) ([http://www.naho.ca/english/pub\\_research.php](http://www.naho.ca/english/pub_research.php)).

Inuit Tapiriit Kanatami, representing five regional Inuit organizations, has partnered with the Nunavut Research Institute to produce "Negotiating Research Relationships with Inuit Communities: A Guide for Researchers" (ITK and NRI, 2007) and a series of pamphlets on research ethics in collaboration with the Ajunnginiq Centre of NAHO.

The Native Women's Association of Canada (NWAC) established a research presence with the mounting of *Sisters In Spirit* research and community action initiative to bring to public awareness the tragedy of missing and murdered Aboriginal women in Canada. NWAC's publications include a statement of the research methods and ethics that guide their work with the families of vulnerable women (NWAC, 2005).

SSHRC in 2003 announced a strategic grants program in Aboriginal research that set as a priority shifting from research “on and about Aboriginal people” to research “with and by Aboriginal people.” NSERC for some years has adapted program guidelines for northern research to engage collaboratively with Inuit and other northern communities in research that includes a focus on environment and nutrition.

UNESCO’s “Universal Declaration on Bioethics and Human Rights” (2005) gave specific attention to interests of Indigenous peoples in research affecting them and the role of communities in providing consent for such activities. The United Nations Declaration on the Rights of Indigenous Peoples gave further specificity to the right of Indigenous peoples to self-determination and their collective right to exercise control over expressions of their cultural heritage and intellectual property. (United Nations, 2007)

The content and research approaches detailed in these documents were informative in designing ethical guidelines adapted to current realities. By far the most intensive activities to engage First Nations, Inuit, and Métis communities directly were undertaken by CIHR-IAPH in drafting and reviewing their emerging guidelines.

### **CIHR Guidelines for Health Research Involving Aboriginal People**

The special ethical challenges presented in research involving Aboriginal people were identified in Section 6 of the TCPS (1998), which set out some best practices based on guidelines developed by other agencies including RCAP and the Inuit Circumpolar Conference. With the creation of the Institute of Aboriginal Peoples’ Health (IAPH) as one of the thirteen CIHR institutes, dedicated to research that would enhance Aboriginal health, the need to address those challenges and provide clear guidance to researchers became an urgent priority. CIHR-IAPH, collaborating with the CIHR Ethics Office and with extensive involvement by the Aboriginal and

research communities, proceeded to develop guidelines for health research, broadly defined, over a five-year period (2002-2007).

The experience with health research for Aboriginal communities has not always been positive. In fact, many Aboriginal people regard research as a process that does not serve their needs either individually or collectively. Moratoria on health research have been initiated by some communities despite pressing needs for better knowledge to contribute to improving health and health care. Communities are simply demanding greater control of factors affecting their lives including having a say on research priorities, a role in the creation and application of new knowledge, and building capacities in an advanced knowledge environment.

In 2002, the IAPH scientific director presented a motion to a senior management committee for planning and priorities, chaired by the CIHR President and CEO and including membership by the thirteen scientific directors of institutes. The motion called for approval of the development of guidelines for research ethics involving Aboriginal peoples to be applied to all Aboriginal health research funded by CIHR. The motion was approved by consensus. In 2002, the CIHR Standing Committee on Ethics approved the detailed plan and subsequently recommended that the CIHR Governing Council adopt the guidelines as policy. The Guidelines were approved by consensus on March 21, 2007.

An Aboriginal ethics working group was struck and conferred over a two-year period to produce the first draft guidelines, drawing on their experience in the field and background papers and studies commissioned by CIHR. Draft guidelines were revised during extensive preliminary consultations undertaken with Aboriginal communities and individuals. Comprehensive national consultations on draft guidelines took place as follows: Round 1 introduced the idea in a national workshop with Aboriginal and research communities (2005); followed by Round 2 (2005-06), a



web-based consultation that was targeted to the broader research community and general public. Concurrently, CIHR conducted on-site meetings involving research-intensive institutions and Aboriginal communities.

The scope of consultations and vetting of guidelines included outreach to northern Aboriginal communities, with meetings in the Northwest Territories, Yukon, and Nunavut. The eight CIHR-IAPH funded Aboriginal Capacity and Developmental Research Environment (ACADRE) networks helped engage the regional views of Aboriginal individuals, communities and Elders and further ensured widespread consultation across Canada. Federal Government consultations included Health Canada, Indian and Northern Affairs Canada and Justice Canada. Partners in the endeavour included the National Council on Ethics in Human Research and the Interagency Advisory Panel on Research Ethics.

The aim of developing guidelines was to connect Aboriginal community interests to researchers and research-intensive institutions. Research is multi-disciplinary as envisioned by the CIHR Act (2000), including the four pillars or domains of biomedical, clinical, population health, and health services research. Nested within research domains, health research disciplines employ an astounding array of methods and tools, which can be connected together in multi-disciplinary, cross-disciplinary, and inter-disciplinary investigations of Aboriginal health. Engaging at the interface between the exceedingly complex and sensitive landscape of Aboriginal community world-views and the equally complex scientific discourse of CIHR funded researchers required clear guidance.

In addition, knowledge translation (KT) to inform policy development is critical for evidence-based programs and services. Guidelines attempt to create a space for community level involvement in research, which seeks to improve population health through integration of ‘real-

time' knowledge translation. KT is imbedded in the process of doing research in partnership with Aboriginal communities and policy makers, thereby promoting rapid application of evidence.

This initiative in public policy was ground-breaking in Canada, introducing research ethics policy of nation-wide application, specific to health research involving Aboriginal people. The policy focused on providing an ethical framework that incorporates Aboriginal world views to address key issues such as: research partnerships; methodology; collective and individual consent; protection of cultural knowledge; benefit sharing; and, collection, use, storage, and secondary use of data and biological samples. The development of research agreements was emphasized as a vehicle for enabling communities to engage in research and, over time, build a foundation of trust with researchers.

In addition to the specific protections articulated in the Guidelines, two core processes for peer evaluation of research are built into review procedures within CIHR: first, to meet (or exceed) community standards for engagement and knowledge creation and, second, to meet (or exceed) international standards for scientific excellence. The anticipated outcome is research that is responsive, rigorous, and linked to improvements in health for communities.

From the outset CIHR guidelines were strategically developed to inform revision of the TCPS (1998) and specifically to feed into a robust, current policy statement building on Section 6. This is not to say that the CIHR Guidelines were intended to be the revision but a starting point to be fully articulated during the TCPS revision process. While the tri-council policy process was proceeding, a clear set of guidelines would be enabling for researchers not familiar with research issues in communities. The development of CHIR guidelines would encourage health research and clarify the ethical conditions on which it could proceed.

The CIHR Guidelines recognize unique cultural, linguistic, historic, and economic differences that exist in relationships between Aboriginal communities and scientific researchers. They create space for co-existence and mutual respect in health research. Publication of the Guidelines stimulated communication and collaboration between CIHR and health research agencies in Australia, New Zealand, and United States. The World Health Organization has recognized the need for a research agreement template, such as the one referenced in the CIHR Guidelines, to guide partnerships between researchers and Aboriginal communities. Circumpolar countries and low and middle income nations have expressed interest in CIHR's Guidelines to inform and update their own guidelines.

#### **PRE's Aboriginal Research Ethics Initiative (AREI)**

The Interagency Advisory Panel on Research Ethics (PRE) is a voluntary group of twelve members drawn from diverse disciplines, universities and research organizations across Canada. The Panel's mandate includes education and interpretation as well as evolution of the TCPS to address emerging ethics issues. Work is carried out with the assistance of a small Secretariat on Research Ethics and working groups that provide access to the expertise of a broader representation of the research and ethics communities. The Panel has commissioned papers to support analysis of specific topics. In the case of Aboriginal research ethics, background research has been shared with CIHR-IAPH and supplemented by papers and workshop reports produced during the development of the CIHR Guidelines.

With the endorsement of the Presidents of CIHR, SSHRC, and NSERC, PRE set a priority on developing a chapter devoted to Aboriginal research integrated in the prospective update of the TCPS. Guidance on ethics of research involving Aboriginal peoples would thus apply to all domains of research conducted by institutions and researchers eligible to receive

funding from the three federally-mandated research Agencies. The Aboriginal Research Ethics Initiative (AREI) was launched in 2003 with the appointment of an Aboriginal member (Castellano) to the Panel and the convening of a strategy meeting involving the three research Agencies and representatives of Aboriginal organizations.

The approach adopted was to create a Guiding Consortium which would engage the Agencies and five Canadian national Aboriginal organizations (NAOs) with PRE in ongoing dialogue to shape the new policy on ethics of Aboriginal research. The Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK), the Métis National Council (MNC), the Congress of Aboriginal Peoples (CAP), and the Native Women's Association of Canada (NWAC) participated in drafting terms of reference for the Consortium. The organizations agreed to involve their constituents and PRE made a commitment to incorporate the Consortium's consensus recommendations on policy or, if consensus was not possible, to represent divergent views in PRE's report to the Agency presidents. On the advice of the Aboriginal representatives, federal ministries were invited to participate in discussions as non-voting members. Health Canada, Indian and Northern Affairs Canada, and Statistics Canada took up the invitation.

The Canadian NAOs through their regional networks were knowledgeable about research needs and activities in their communities and were taking an increasing interest in governance of research. The First Nations Information Governance Committee, which oversees the First Nations Regional Health Survey, articulated the principles of Ownership, Control, Access and Possession ([http://www.naho.ca/english/pub\\_research.php](http://www.naho.ca/english/pub_research.php)), which have been endorsed and adapted in numerous First Nations communities across Canada. ITK, in collaboration with regional representatives and the Inuit Centre of NAHO, undertook to develop an Inuit-specific platform for ethics of research in the Arctic. NWAC makes available, on its website, their

commitment to participatory research methods and ethical practice in *Sisters in Spirit* research. MNC, in collaboration with the Métis Centre at NAHO, is working on Métis -specific practice guidelines. Between 2004 and 2008 the Secretariat on Research Ethics made available modest grants to the NAOs to assist with engaging their regional constituents.

To complement the policy advice sought from the Consortium, PRE also convened a Technical Advisory Committee on Aboriginal Research (PRE-TACAR), made up of Aboriginal and non-Aboriginal practitioners in academic and community research settings. PRE-TACAR helped to identify issues and review working papers drafted by the Secretariat on Research Ethics and the chair of AREI. In engaging the broader research community, the chair of AREI made numerous presentations at conferences and seminars, involving Aboriginal and non-Aboriginal researchers, to invite commentary on the perspectives and priorities for an Aboriginal chapter that were crystallizing.

To test and refine policy options in the thirteen (current) chapters of the revised TCPS PRE publishes issue and area-specific working papers on its website (<http://www.pre.gc.ca>). An issues discussion paper, including illustrative case studies on Aboriginal research ethics, was released in electronic form in the spring of 2008. A complete draft of a revised TCPS text was published electronically and in hard copy to solicit public comment in December 2008 (PRE: 2008). The Secretariat and Panel members participated in over 50 consultation meetings and focus groups, some targeted to Aboriginal researchers, at universities and research institutes across the country in subsequent months. More than 220 written submissions were received, with Chapter 9 on Research Involving Aboriginal Peoples receiving the highest volume of comments. At the time of writing, review and analysis of comments are being incorporated in a second draft of a revised TCPS slated for public release in December 2009. The National Aboriginal

Organizations participating in the Consortium are engaging their constituents in review of policy drafts.

The guidance provided in Chapter 9 is based on the premise that engagement with community is integral to ethical research involving Aboriginal peoples. Community is defined as a collectivity with shared interests or identity that has the capacity to act or express itself as a group. Communities may be territorial, organizational, or a community of interest with more fluid boundaries. Engagement can take many forms, including consent 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 level of engagement may range from information sharing to active participation and collaboration, to empowerment and shared leadership of the research project. A key aspect of ethical practice is respect for community customs and codes of research practice relevant to the research project. Articles in the chapter provide explicit guidance for putting these basic ethical practices into effect.

Chapter 9 of the draft TCPS and the CIHR Guidelines share the same goal – to create an ethical space where Canadian Aboriginal communities and researchers can come together with mutual respect and a degree of trust that has often been lacking in research encounters. The two documents embody many of the same practice guidelines but they are not identical. The TCPS is the platform on which institutional policies adapted to particular circumstances stand. As an over-arching policy it must be applicable to the research domains of the Agencies that endorse it – CIHR, SSHRC and NSERC – and therefore sets out principles as well as prescriptions that must be complemented by ethical reflection and judgment in diverse venues.

Researchers and the NAO representatives commenting on the 2008 draft of the TCPS perceived significant differences from the CIHR Guidelines and asked for clarification of how the two policies would work together. PRE and the Secretariat are working with CIHR Ethics Office, IAPH, SSHRC, and NSERC to make revisions that show the correspondence between the documents more clearly and to narrow or resolve points of divergence.

The second draft of the revised TCPS is scheduled for release in December 2009 with opportunity for comment extending to March 1, 2010. The revised draft of Chapter 9 will be available earlier, at the end of October 2009, in response to requests for additional time for circulation in the Aboriginal community. PRE's goal is to have a revised TCPS, which has broad support, ready for submission to the Agency presidents in the spring of 2010.

### **Policy Writing as Dialogue**

Policy to guide ethical research involving Aboriginal peoples is evolving in the unique social and political environment of Canada. Reflecting on the process may, nevertheless, prove of value to other Nation States and Indigenous peoples setting out on a similar course.

The Canadian *Constitution Act* of 1982 recognizes and affirms the Aboriginal and treaty rights of Aboriginal peoples, including Indian (First Nations), Inuit, and Métis peoples in Canada. While the nature and extent of such rights are still being defined, constitutional protection creates an obligation on public institutions to acknowledge and support the desire of Aboriginal peoples to maintain their collective identities and the continuity of their cultures.

Ethics policy for Aboriginal research in Canada, whether specific to health or applying more broadly to all research domains, should therefore be responsive to both individual wellbeing and collective welfare as conceived by the people involved. Research that engages the community and that addresses concerns relevant to the people, that builds on traditional

knowledge, and that enhances local capacity holds the greatest promise of contributing to that goal.

*Writing* policy carries some inherent contradictions, when attempting to incorporate First Nations, Inuit, and Métis ethics of “good relations” and institutional requirements for enforceable rules. Translating predominantly oral custom into a written code, or vice versa, introduces the potential for distorting meaning and furthering misunderstanding. The development process followed by CIHR and PRE has been to consider carefully the guidance available in emerging codes of community practice in Canada and the approaches taken in other countries including Australia, New Zealand, and United States. Drafts of ethics policy were discussed in numerous face-to-face meetings conducted by CIHR-IAPH with community participants and in on-line consultations connecting with Aboriginal and non-Aboriginal researchers. National Aboriginal organizations with regional networks have been involved in reviewing and advising on revisions to drafts

The CIHR Guidelines and the proposed revision of the TCPS carry with them two important provisions: First, they are represented to the Aboriginal community as living documents, which will be subject to interpretation and updating through the continued participation of Aboriginal researchers and community representatives. The dialogue on policy, undertaken between 2002 and 2009, will continue. Second, both documents seek to create “ethical space” at the place where communities and researchers meet. Different worldviews, needs, and expectations between the parties can be expected to present challenges. Dialogue undertaken with an ethical commitment to mutual benefit and good relations can be a powerful instrument to prevent violations of human dignity.



The experience of CIHR-IAPH in the two-and-a-half years since the CIHR Guidelines were approved indicates that policy adoption is only the first step in effecting change. A major educational effort is required to equip research ethics boards to interpret and apply innovative guidelines. At the same time, Aboriginal communities struggle to secure the resources that will enable them to become full partners in initiating, guiding, and making use of research to reach self-determined goals.

Whereas research institutions receive earmarked funding to offset the costs of administration and ethical oversight of research, Aboriginal communities have no access to these resources. The expectation that Aboriginal communities will co-venture and engage in complex partnership arrangements, as stipulated by the CIHR Guidelines and potentially the revised TCPS, can only be met if a parallel commitment is made to support the development of community research capacity for ethical oversight and administration. Indirect costs must be integrated into the funding formulas of national granting councils so that Aboriginal communities receive equitable treatment, with earmarked funding comparable to support received by institutional partners for administrative costs and workforce development.

Ethical guidelines alone do not tackle important issues related to the governance of research ethics. With increased involvement at the community level questions of local conflict of interest are inevitable. Some Canadian First Nations communities have created regional ethics review processes, for example the Manitoulin Island Ethics Board in Ontario and the Mi'kmaq Ethics Watch in Nova Scotia. These bodies provide a critical mass of expertise not available in a single community. They are close enough to the culture of the community to reflect local concerns but a step removed from the dynamics of community relationships and obligations.

Discussions regarding creation of a national ethics review body have stalled due to reluctance to hand over control of important community decisions to a faceless, distant agency. Linking communities with extensive experience in ethics review with newer participants in research through a networked, Aboriginal ethics governance body has yet to be tried, to the knowledge of the present authors. Testing this or another model will require that the Canadian Federal Government invest in building Aboriginal capacity to engage in the dynamic evolution of research practice and research ethics.

The knowledge society of the 21<sup>st</sup> century requires nothing less than the fullest development and creative contribution of all its citizens. Indigenous scholars in Canada and around the world are articulating the contours of Indigenous knowledge and asserting its relevance to contemporary life. The engagement of First Nations, Inuit and Métis peoples, in dialogue to devise policy on ethics of research involving humans in Canada, clearly demonstrates that they are eager to take up the challenges of knowledge creation, knowledge translation and knowledge application for the benefit of their communities and society at large.

It is hoped that this description of the Canadian experience of revising national research ethics policies to include guidelines for research with Aboriginal peoples may provide insight to other national jurisdictions interested in developing their own research ethics protocols for engagement with indigenous populations.

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