

Ethics of Aboriginal Research

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Abstract

This paper proposes a set of principles to assist in developing ethical codes for the conduct of research within the Aboriginal community or with external partners. It places the discussion of research ethics in the context of cultural world view and the struggle for self-determination as peoples and nations. It affirms that Aboriginal Peoples have a right to participate as principals or partners in research that generates knowledge affecting their culture, identity and well-being. To provide context and rationale for the principles presented, the paper outlines features of the current public dialogue on research ethics, how ethics are framed in Aboriginal cultures, and how Aboriginal perceptions of reality and right behaviour clash with norms prevailing in western research. Current initiatives of Aboriginal communities and nations, research granting councils and institutions to establish ethical guidelines for Aboriginal research are highlighted as evidence that the development of workable ethical regimes is already well begun.

Key Words

Aboriginal, Canada, ethics, research, world view, identity, culture-clash, principles, guidelines

INTRODUCTION

In September 1992, the Royal Commission on Aboriginal Peoples (RCAP) brought together about 80 Aboriginal Peoples who were involved in research as academics, lawyers, graduate students, project staff and consultants, community leaders, and Elders. We met at a workshop at Nakoda Lodge in Alberta to shape the emerging research agenda of RCAP. As Co-Director of Research, I was the chairperson of the initial session in which numerous participants voiced harsh criticism of past research and serious scepticism that RCAP research would serve them any better. "We've been researched to death!" they protested. The workshop was not off to a promising start, until an Elder who had opened the meeting spoke quietly from a corner of the room. "If we have been researched to death," he said, "maybe it's time we started researching ourselves back to life."

That piece of wisdom has been repeated often in the past 10 years. It was prophetic of the change that would gather remarkable momentum in just a decade. Aboriginal knowledge has always been informed by research, the purposeful gathering of information and the thoughtful distillation of meaning. Research acquired a bad name among Aboriginal Peoples because the purposes and meanings associated with its practice by academics and government agents were usually alien to the people themselves and the outcomes were,

as often as not, misguided and harmful. Aboriginal Peoples in organizations and communities, as well as universities and colleges and some government offices, are now engaged in transforming Aboriginal research into an instrument for creating and disseminating knowledge that once again authentically represents ourselves and our understanding of the world.

Researching ourselves may mean self-initiated action or it may mean entering into effective partnerships. In either case, the ground rules that should guide new practices are not immediately evident. Where Aboriginal expectations diverge from past practice, resistance from the academic research establishment is to be expected.

This paper proposes a set of principles to assist in developing ethical codes for the conduct of research internal to the Aboriginal community or with external partners.¹ The context and rationale for these principles is developed in early sections outlining the current dialogue on research ethics, how ethics are framed in Aboriginal cultures, and how Aboriginal perceptions of reality and right behaviour clash with prevailing norms of western research. Efforts of Aboriginal communities and nations, as well as research granting councils and institutions, to establish ethical guidelines for Aboriginal research are highlighted as evidence that the development of workable ethical regimes is already well begun.

In this paper:

Research means activity intended to investigate, document, bring to light, analyse, or interpret matters in any domain, to create knowledge for the benefit of society or of particular groups.

Aboriginal refers to First Nations, Inuit and Métis Peoples as referenced in the *Canadian Constitution*. Indigenous is used interchangeably with Aboriginal, usually in international contexts. Where sources refer to specific groups, such as First Nations, the terminology of the source is retained.

Aboriginal research means research that touches the life and well-being of Aboriginal Peoples. It may involve Aboriginal Peoples and their communities directly. It may assemble data that describes or claims to describe Aboriginal Peoples and their heritage. Or, it may affect the human and natural environment in which Aboriginal Peoples live.

Ethics refers to rules of conduct that express and reinforce important social and cultural values of a society. The rules may be formal and written, spoken, or simply understood by groups who subscribe to them.

The language, images and perspectives in this paper are those of a Mohawk woman and academic of a certain generation. I suggest that the principles I articulate are relevant more broadly to Aboriginal research, though readers from other cultures, particularly Métis and Inuit colleagues, will undoubtedly need to do some translation to connect my words with their own world views and experiences.

AN ACTIVE DISCOURSE ON RESEARCH ETHICS

International concern about research ethics arose from revelations in the Nuremburg trials of atrocities committed in experimentation on humans by the Nazis during the Second World War. To prevent future violations of human rights in the name of science, western nations developed the Nuremburg Code representing broad international agreement on ethical standards in medical research. The Nuremburg Code was replaced by the Helsinki Declaration, which was adopted in 1964 and subsequently updated.² Ethical codes place emphasis on informed consent and are intended to strike a balance between the risk incurred by participants and the potential benefit of the research to society.

In Canada, research ethics in universities and publicly-funded research institutes are guided by the Tri-Council Policy Statement,³ adopted jointly by the

major research granting councils: the Natural Sciences and Engineering Research Council (NSERC), Social Sciences and Humanities Research Council (SSHRC), and Canadian Institutes of Health Research (CIHR), formerly the Medical Research Council. The three councils receive funding from the federal government for distribution to research bodies across Canada.

Current ethical guidelines and the governance structures through which they are administered are being reviewed because a number of shortcomings have been identified:⁴

- Ethical guidelines are administered on a voluntary basis through a patchwork of procedures and institutions. Universities and research institutes administering research grants from the granting councils are expected to adopt procedures consistent with the Tri-Council guidelines as a condition of funding. There is some follow-up to ensure that this occurs. Academic and professional associations, anthropologists and psychologists for example, also develop guidelines which their members are expected to follow. Governments' contracts are generally silent on the subject of ethical compliance, relying on researchers to abide by the ethics of their profession or institution.
- Universities have ethics committees. They are responsible for administering the institution's guidelines for research on human subjects. The committees review research proposals for compliance with ethical guidelines as a condition for approving the flow of funds through the university to the principal investigator(s). Once the proposal is approved, there is no provision for monitoring how the research is actually conducted.
- Ethics committees are perceived to focus on the procedure proposed for obtaining informed consent from human subjects involved in research. The ethical character of the research project itself is generally not examined.
- There are no sanctions available to discipline researchers who violate existing ethical guidelines, beyond complaints to universities or professional associations with which they are affiliated.
- Research that is funded by individuals or corporations independent of a university or research institute is not subject to publicly approved ethical guidelines. Corporations funding research in collaboration with public institutions may have commercial interests that conflict with institutional ethics and may exert pressure to override ethical concerns that arise.

- Advances in medical research, for example reproductive technology and genetic research, have raised public concern about research ethics that are not adequately dealt with by fragmented and voluntary guidelines.
- The federal government is a major funding source, directly and indirectly, of research involving human subjects. It relies on other agencies to ensure that an ethical balance between benefit and risk is maintained in much of the research that it funds. This leaves open questions about the adequacy of safeguards of the public interest.

Aboriginal Peoples interested in research share the concerns cited above and welcome the current review of principles and processes for governing research involving human subjects. However, even if ethical oversight of research sponsored by public institutions is made more consistent, up-to-date and enforceable, there is a danger that concerns particular to Aboriginal Peoples will be neglected or made subject to inappropriate regulation.

It is essential that Aboriginal Peoples and their organizations put forward, not only concerns, but also solutions to the ethical problems that too often have made research affecting them inaccurate and irrelevant. Reframing ethical codes and practice is necessary to ensure the social benefit that motivates research also extends to the Aboriginal Peoples whose universe is being studied.

AN ABORIGINAL PERSPECTIVE ON ETHICS

Descriptions of Aboriginal societies seldom speak of the ethics that support order, cohesion and personal responsibility in those societies. Anthropological studies document customs that sometimes have the character of law. Dr. Clare Brant, a Mohawk physician who became the first Aboriginal psychiatrist in Canada, wrote an influential paper entitled *Native Ethics and Rules of Behaviour*. In it, he used the language of ethics to illuminate some powerful, unspoken assumptions that guide behaviour he observed in his Iroquoian, Cree and Ojibway patients. Brant's elaboration of the ethic of non-interference, which inhibits argument and advice-giving as normal means of communication, is particularly relevant for researchers and professionals offering services to Aboriginal Peoples. While non-interfering behaviour may be perceived as passive and irresponsible, Brant points out that it is consistent with teaching based on non-intrusive modelling rather

than direct instruction that attempts to shape the behaviour of the learner.⁵

Traditional teachings are conveyed through example, through stories and songs, in ceremonies and, most importantly, through engagement with the natural world which is governed by laws of life just as human beings are. A recent initiative in Saskatchewan documented the language used by Elders sharing their knowledge of culture, history and treaty making in their various nations. Elder Peter Waskahat spoke of the foundations of knowledge and the connections between land, family, spirituality, values, and everyday living:

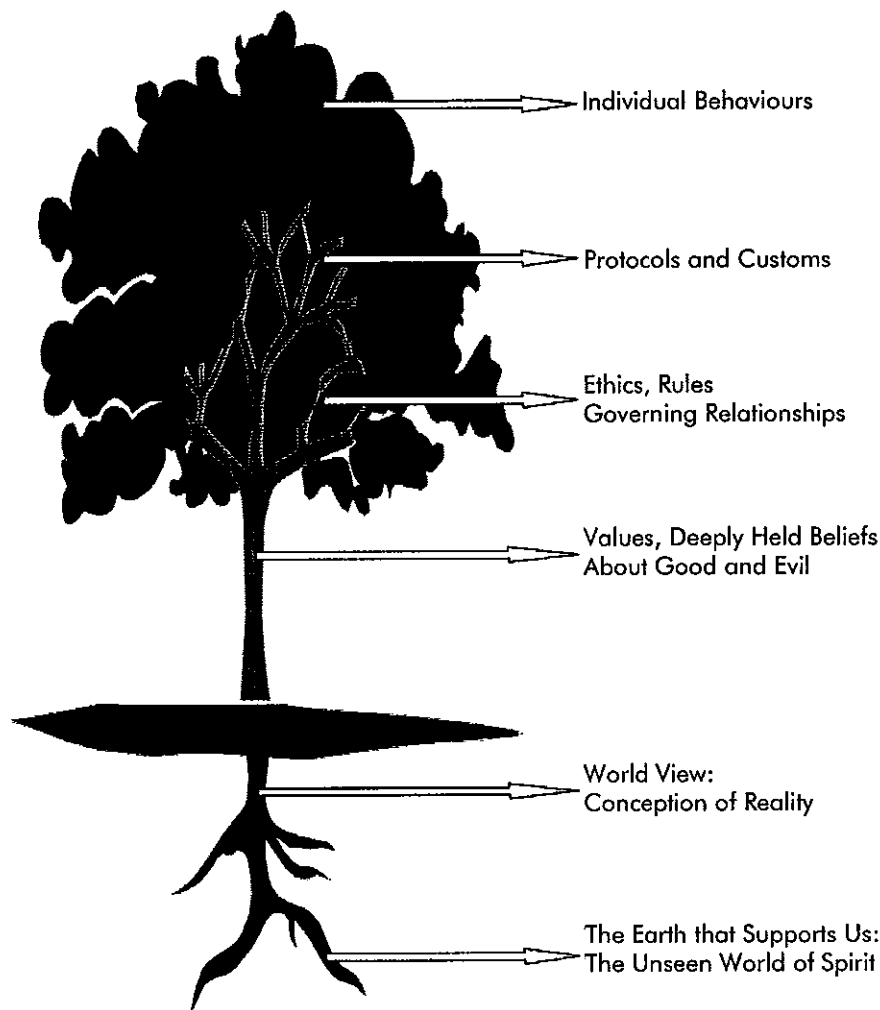
We had our own teachings, our own education system – teaching children that way of life was taught by the grandparents and extended families; they were taught how to view and respect the land and everything in Creation. Through that the young people were taught how to live, what the Creator's laws were, what were the natural laws, what were these First Nations' laws... the teachings revolved around a way of life that was based on their values.⁶

When Aboriginal Peoples speak about maintaining and revitalizing their cultures, they are not proposing to go back to igloos and teepees and a hunter-gatherer lifestyle. They are talking about restoring order to daily living in conformity with ancient and enduring values that affirm life. The relationships between individual behaviour, customs and community protocols, ethics, values, and world view are represented in Figure 1 using the symbol of a tree.

The leaves represent individual behaviours. Protocols and community customs are small branches while ethics, the rules governing relationships, are the large branches. Values, deeply-held beliefs about good and evil, form the trunk of the tree. The world view or perception of reality underpinning life as it is lived, like the roots of the tree, is not ordinarily visible. The whole of the tree is rooted in the earth which supports us. In this symbolic representation, I suggest that the earth is like the unseen world of spirit – vast, mysterious and friendly if we learn how to respect the laws that govern it.

Some nations have codified their ethical systems. The Iroquois Great Law of Peace teaches the importance and the requirements of cultivating a "good mind" in order to live well and harmoniously in the

Figure 1: The Context of Aboriginal Ethics



world. The potlaching ceremonies of West Coast nations were public means of validating genealogies, family responsibilities, inheritance rights, and land tenure. Many other nations transmitted their ethical codes orally and non-verbally through family and community relationships. Public ceremonies reinforce the community's world view and provide instruction for living. Skills for decoding complex messages from the social and natural environment are embedded in traditional languages.

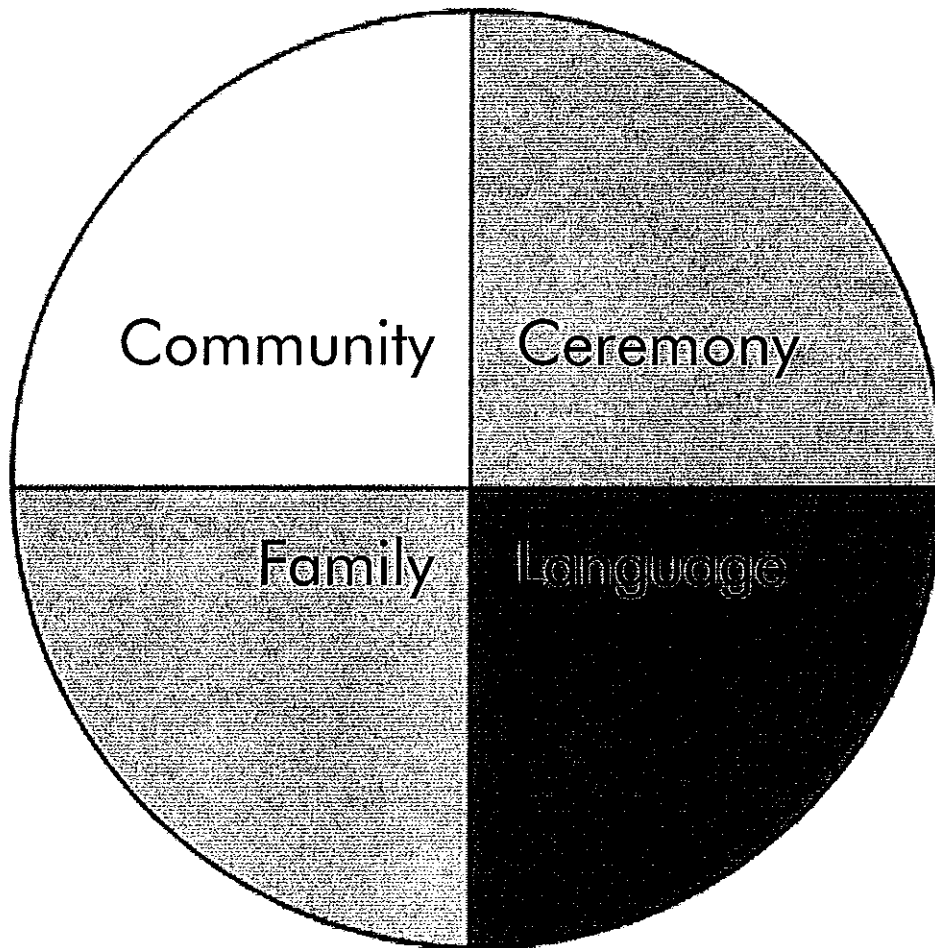
The persons who are most knowledgeable about physical and spiritual reality, the teaching and practice of ceremonies, and the nuances of meaning in Aboriginal languages, are Elders. Elders typically have been educated in the oral tradition, apart from the colonizing influence of the school system. They carry credentials that are recognizable within Aboriginal society, but invisible to those who assess expertise on the basis of formal education. They enjoy respect as sources of wisdom because their way of life

expresses the deepest values of their respective cultures. In many cases, they have exceptional skills in transmitting these values to those who seek their counsel.

The mutually reinforcing means of transmitting Aboriginal world views, guided by the wisdom of Elders, are represented in Figure 2. Language, which carries the code for interpreting reality, is learned within the family and reinforced by the practices and values endorsed by the community. Public ceremonies and private rituals give shared expression to teachings. In turn, these become incorporated in the language of family and community relations.

The misguided policies that sought to undermine the role of language and the influence of family, community and ceremony in shaping individual and community life have been thoroughly documented and critiqued in recent years.⁷ RCAP, mapping the choices necessary to navigate a turning point in Aboriginal/Canadian relations, wrote:

Figure 2: Transmission of Aboriginal World View



Another fundamental issue is the need for Canadians to recognize that Aboriginal cultures were vibrant and distinctive not only in the beginning but remain so today. Though bruised and distorted as a result of the colonial experience, inevitably changed by time and new circumstances, even in danger of extinction in some important dimensions such as language, nevertheless a fundamentally different world view continues to exist and struggles for expression whenever Aboriginal Peoples come together.⁸

Within Aboriginal communities, the struggle has gone beyond survival as small enclaves set apart from non-Aboriginal Canada. The struggle now extends to applying cultural ways in the management of lands and economic activity; the structures of governance; the provision of health, education, justice and other human services; and relations with the larger Canadian society and the world community. The struggle is to live and thrive as peoples and nations

maintaining and expressing distinctive world views and contributing uniquely to the Canadian federation. In the language of the United Nations Working Group on Indigenous Populations, this is the pursuit of self-determination.

Indigenous peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.⁹

Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable. Just as colonial policies have denied Aboriginal Peoples access to their traditional lands, so also colonial definitions of truth and value have denied Aboriginal Peoples the tools to assert and implement their knowledge. Research under the control of outsiders to the Aboriginal community has been instrumental in rationalizing colonialist per-

ceptions of Aboriginal incapacity and the need for paternalistic control.

Aboriginal scholars who have been educated in western universities and who are conversant with Aboriginal ways of knowledge-seeking are challenging western assumptions and methodologies of research. In the study of Elders' language referred to earlier, the authors explain:

The Elders' comments allude to formal and long-established ways, procedures, and processes that First Nations persons are required to follow when seeking particular kinds of knowledge that are rooted in spiritual traditions and laws. The rules that are applied to this way of learning are strict, and the seekers of knowledge are required to follow meticulous procedures and processes as they prepare for and enter the "quest for knowledge journey."¹⁰

In the world of Aboriginal knowledge, a discussion of ethics cannot be limited to devising a set of rules to guide researcher behaviour in a defined task. Ethics, the rules of right behaviour, are intimately related to who you are, the deep values you subscribe to, and your understanding of your place in the spiritual order of reality. Ethics are integral to the way of life of a people. The fullest expression of a people's ethics is represented in the lives of the most knowledgeable and honourable members of the community. Imposition of rules derived from other ways of life in other communities will inevitably cause problems, although common understandings and shared interests can be negotiated. This is the ground on which Aboriginal Peoples stand as they engage in dialogue about research ethics that will limit the risks and enhance the benefits of research affecting their lives.

"JAGGED WORLDVIEWS COLLIDING"

Leroy Little Bear coined the phrase "jagged worldviews colliding" to describe the encounter of Aboriginal philosophies and positivist scientific thought.¹¹ Aboriginal world views assume that human action, to achieve social good, must be located in an ethical, spiritual context as well as its physical and social situation. Scientific research is dominated by positivist thinking that assumes only observable phenomena matter. Little Bear points out that much externally-sponsored research has documented customs, but missed the deeper significance of those customs:

[Anthropologists] have done a fairly decent job of describing the customs themselves, but they have failed miserably in finding and interpreting the meanings behind the customs. The function of Aboriginal values and customs is to maintain the relationships that hold creation together.¹²

Research was defined earlier in this paper as knowledge creation for social benefit. If researchers and those researched have vastly different notions of what constitutes social benefit and how it is achieved, the research is unlikely to satisfy the needs and expectations of participants on both sides of the divide. This section outlines some of the issues that arise in devising ethical regimes that are appropriate for Aboriginal research.

Should ethics be restricted to research on human subjects?

In Aboriginal knowledge systems, the boundary between material and spiritual realms is easily crossed. Similarly, the boundaries between humans, animals, plants, and natural elements are also permeable. This is represented in traditional stories of communication between humans and other beings, and transformation of persons into animals and sea creatures, or vice versa.

The inter-dependent relationship between humans and natural elements was described by Simon Lucas, a B.C. Elder speaking at an RCAP hearing:

The sea and its resources is the heart and soul of our people. Sea resources have sustained our people since time began for us. The health of the ocean means a healthy emotion. It has a direct impact on our mental state. A healthy ocean means a healthy state of mind for us. The health of the ocean means the assurance that my body is going to stay healthy. That is important for people to understand. My spirituality, the spirituality of our forefathers, was tied directly to the ocean. The health of the ocean means that my spiritual well-being is going to stay intact.¹³

Scientific research conflicts with Aboriginal sensibilities when it sets ethical guidelines for research involving human subjects, but assumes that the earth and the waters are inanimate or lifeless, and that mice, monkeys or fish can be treated as objects of research rather than co-inhabitants with humans of a living

biosphere. Because many Aboriginal societies maintain primary dependence on a healthy natural environment to meet their needs, industrial development that sacrifices environmental values directly infringes on their well-being and human rights. Ethical regimes for Aboriginal research must therefore extend beyond current definitions of research involving human subjects to include research that affects Aboriginal well-being. This includes environmental research that will impact their physical environment or archival research that may perpetuate negative or inaccurate representations of Aboriginal Peoples.

Maintaining a balance between reductionist analysis and holistic vision

The prevailing model of scientific inquiry reduces the scope of analysis to smaller bits of reality that can then be analysed with greater specialization. This is referred to as a reductionist approach. Research that takes measures to exclude variables or influences from the environment that might contaminate cause-effect sequences is applauded as more reliable than data about complex and unexplainable lived experience. Social sciences exploring human experience have adopted scientific method as the hallmark of their credibility even though human behaviour is subject to many variables that interrupt linear cause-effect sequences. The science of ecology has emerged as an approach to understanding the interdependence of elements and processes in the natural world, to some extent countering the dominance of reductionist research. However, the role of intuitive insight or vision in scientific breakthroughs is regularly downplayed in western disciplines and institutions.

In contrast, the heart of Aboriginal science acknowledges the spirit of the plant, animal or the land and the importance of relationships in supporting life. Gregory Cahete, a Tewa educator, writes:

Native peoples through long experience and participation with their landscapes have come to know the language of their places. In learning this language of the subtle signs, qualities, cycles and patterns of their immediate environments and communicating with their landscapes Native people also come to know intimately the "nature" of the places which they inhabit. Learning the language of place and the "dialects" of its plants, animals, and natural phenomena in the context of a "homeland" is an underlying foundation of Native science.¹⁴

Aboriginal science does not ignore analysis of the particular. In fact, the perception of patterns is synthesized from multiple keen observations. The teaching device of the medicine wheel applied in Figure 2 fosters awareness that any particular event or phenomenon functions as part of a larger whole.

Holistic awareness and highly focussed analysis are complementary, not contradictory. There are examples of effective partnership between communities and scientists. The Sandy Lake Health and Diabetes Project in northwestern Ontario has brought together clinical treatment, community-based prevention strategies, and participation in genetic studies.¹⁵ The Akwesasne Mohawk community enlisted scientists from Cornell University to assist in verifying the nature and degree of pollution that was destroying the health of their crops and animals. Too often, however, perceptions and concerns at the community level are dismissed as anecdotal while priority setting for research proceeds on a different track.

"A living, dialogical relationship with the world"

This phrase is drawn from Marie Battiste and James (Sa'ke'j) Youngblood Henderson's work on *Protecting Indigenous Knowledge and Heritage*.¹⁶ It encapsulates the Aboriginal ethic that all aspects of the world we know have life and spirit and that humans have an obligation to learn the rules of relating to the world with respect. We enter into mutual dialogue with the many people and other beings with whom we share the world. When you harvest salmon, you are engaging in a reciprocal relationship in which the spirit of the fish gives sustenance to human beings and humans in turn observe the protocols that demonstrate right relationship. When you seek knowledge from an Elder, you offer tobacco or other appropriate gifts to symbolize that you are accepting the ethical obligations that go with received knowledge. In each case, the exchange confirms a relationship that continues beyond the time and place of the exchange. Knowledge is not a commodity that can be purchased and exploited at will.

Because knowledge carries with it power to do good or ill to the knower and the community, many Elders decline to have their knowledge recorded in writing or electronic media. They want to be assured that the seeker is properly instructed and compliant with the ethical obligations that will be assumed.

Information can be gathered by individuals to shape personal perceptions. Aboriginal societies tradi-

tionally were respectful of the unique vision of individuals. However, individual perceptions had to be validated by community dialogue and reflection before they became collective knowledge, the basis of collective action. This was the function of the many councils responsible for family, clan, village, or nation affairs.

Research that seeks objectivity by maintaining distance between the investigator and informants violates Aboriginal ethics of reciprocal relationship and collective validation. If the researcher assumes control of knowledge production, harvesting information in brief encounters, the dialogical relationship with human and non-human sources is disrupted and the transformation of observations or information into contextualized knowledge is aborted. Attempts to gain an understanding of Aboriginal life and concerns from an objective, short-term, outsider vantage point have produced much research that Aboriginal Peoples reject as distortions of their reality.

Where Aboriginal Peoples control access to research sites, for example research on First Nations territories, organizations and local governments are increasingly insisting on community control. This may mean assuming full responsibility for conducting the research or it may mean collaborative research in which the respective responsibilities of community and outside researchers are set out in a contract. Some initiatives to achieve balanced, mutually-respectful partnerships between Aboriginal communities and researchers are described in a later section of this paper.

Who are the owners of Aboriginal knowledge?

The three national granting councils grappled with questions of collective rights and consent in the formation of their joint policy statement in 1998. In the end, the policy avoids taking a definitive position. The preface to Section 6 of the Tri-Council Policy Statement (TCPS) on Aboriginal research states that the best practices cited are guidelines only and that final standards should be developed in consultation with Aboriginal Peoples. Section 6 of the TCPS, Research Involving Aboriginal Peoples, recommends:

When research involves aboriginal individuals, researchers and REBs [research ethics boards] should consider the interests of the aboriginal group, when any of the following considerations applies:

- a. Property or private information belonging to the group as a whole is studied or used.

- b. Leaders of the group are involved in the identification of potential participants.
- c. The research is designed to analyze or describe characteristics of the group.
- d. Individuals are selected to speak on behalf of, or otherwise represent, the group.

The TCPS leaves open for discussion the question of when individuals may be interviewed as individuals without regard to the group as a whole and without seeking permission from any group authority or spokesperson.¹⁷

Darrell A. Posey and Graham Dutfield,¹⁸ in a major study published by the International Development Research Centre, explore numerous violations around the world of Indigenous Peoples' rights to maintain the integrity and derive equitable benefit from their traditional knowledge. They underline the vulnerability of Indigenous Peoples to exploitation and the inadequacy of intellectual property laws to protect knowledge that falls outside the definition of property that prevails in western culture. In particular, state laws provide protection of intellectual property for a limited time if it is attributable to individuals and if it is expressed in a fixed form such as a manuscript, recording or art object. These laws are in direct conflict with Aboriginal norms of collective ownership of traditions handed down from time immemorial and recorded in the memories of Elders. Illegitimate use of Aboriginal knowledge for pharmaceutical and other commercial usage is characterized by Posey and Dutfield and other observers as cultural and bio-piracy. Collecting knowledge from persons who are not authorized to transfer a community's heritage is regarded by Aboriginal Peoples as akin to illegitimate land transfers historically or purchase of sacred artefacts in violation of community ethics on access. Such transactions also violate international norms on consent, which provide that persons giving consent should be competent, that is, aware of the implications of consent and having the authority to give consent where others' interests are involved.

Voluntary consent

In many cases, research in Aboriginal communities and on Aboriginal matters is initiated by agencies from whom Aboriginal Peoples receive essential services. The research is often funded by governments that control resources on which the community depends. Rightly or wrongly, many Aboriginal Peoples fear that refusing to consent to research may result in loss of funding for essential needs. They are at a disadvantage in negotiating conditions that would alter

the imbalance in power between researchers and the community and give adequate recognition to community priorities and approaches to knowledge creation.

Privacy of health data collected routinely in the delivery of services has become a major concern in health research, especially with the possibility of sharing masses of data electronically across borders. Once information is transferred, it becomes difficult to monitor the secondary or tertiary purposes for which it is used.

The Organization for Economic Co-operation and Development (OECD) outlined an influential set of principles for data protection in 1980. The standards put forward mean that only relevant and accurate data should be collected for precise and limited purposes and that disclosure and use should be restricted to those original purposes unless consented to by the data subject or authorized by law.¹⁹

Aboriginal Peoples express concern that use of Census and population health data, once records are stripped of personal identifiers, is not restricted under ethical rules or privacy legislation. Thus, they have no control over assembled information that may be used for unauthorized surveillance or that may reinforce negative stereotypes of them as communities and peoples.

Methodology and validation

Culturally different approaches to knowledge creation imply the need for different methods of gathering and validating information. Participatory research has received a positive reception in Aboriginal communities and has gained acceptance in some quarters of the research community. The study of Elders' language cited earlier provides a detailed description of how the method is applied.

The treaty commissioner for Saskatchewan commissioned documentary research on treaty making from the Crown's perspective. He also commissioned research with Elders on Aboriginal perspectives. Forums were convened with the assistance of the Federation of Saskatchewan Indian Nations, with Elder helpers available to assist with ceremonies and translation of contributions in First Nations languages. Audio and video recordings of meetings were made. Successive translations and interpretations of Elders' words were checked with the Elders themselves to confirm consent and verify accuracy. These reviews resulted in reworking the translations to incorporate both editorial and substantive changes. The final text of *Treaty Elders of Saskatchewan* was published with confidence that it embodies a beginning theoretical

framework grounded in the knowledge of Cree, Saulteaux, Dene, and Assiniboine participants.²⁰

If validating intercultural research and communication seems labour-intensive, time-consuming and expensive, it is because the integrity of knowledge transfer has received too little attention in the past. Aboriginal communities, political organizations and scholars are insisting that the integrity and validity of research cannot be assured by western methodologies alone. They must be tempered by methodologies that are compatible with Aboriginal methods of investigation and validation.²¹

The challenges of bicultural research in Aboriginal communities

Aboriginal Peoples have always conducted research within their communities to update and adapt knowledge. This is the way a people survives in a changing environment.²² Legal and political struggles to assert rights over their lands in the latter decades of the 20th century brought new methods of research into play. Participating in the discourse of courts and governments required expertise in English and French and mobilization of documentary evidence. Preparation of land claims relied heavily on outside consultants to conduct research and prepare arguments, although traditional and experiential knowledge of Aboriginal Peoples provided the foundations and shaped the form of the claims put forward.

Aboriginal lawyers and researchers are assuming increasing prominence in litigation and negotiation of land questions. Both Aboriginal and non-Aboriginal scholars in many domains and disciplines are now working to formulate and express Aboriginal knowledge and ethics that are implied in traditional and more recent bicultural research.

It is difficult to secure resources with the Aboriginal community for research addressing issues that are priorities to insiders. Consequently, much of what is formally called research is addressed to both insider and outsider constituencies. Research under Aboriginal community control, even when it is undertaken with an ethical commitment to respect cultural perspectives, presents a number of challenges.

- Traditional ethics and practices may be fragmented and their applicability to contemporary circumstances unclear, requiring meticulous research and testing to plan effective action. The Harvard Project on American Indian Economic Development has made an important contribution in mapping the role of traditional ethics in the success of economic projects.²³

- As masses of information are collected and stored, Aboriginal citizens have become concerned about privacy, secure storage and management of information, and access to information by outside agencies. There is a vacuum in ethical codes at the community level to address these concerns.
- Aboriginal Peoples are intent on preserving the distinctive character and autonomy of their local communities. Still, they recognize the need to assemble data across communities to address common needs. The mechanisms to achieve these goals in a complementary manner are at early stages of definition.
- Research and information management activities compete with other urgent priorities of direct service in housing, health, education, etc. Long-term planning is overridden by ad hoc responses to crises, perpetuating the conditions that create the crisis.
- Aboriginal citizens, communities and nations are ill-informed about their rights and the options available to protect and preserve their intellectual heritage from misappropriation and misrepresentation, whether research is mounted by insiders or outsiders to their communities.

Encouraging ethical research

If the conflicts generated by “jagged worldviews colliding” remain unresolved, there is a danger that Aboriginal research will undergo a chill. Efforts of Aboriginal communities and organizations to negotiate ethical conditions for research are characterized as attempts to assert control. Despite post-modern critiques that research is captive already to the unacknowledged assumptions of researchers and their cultures, control of research by interest groups is perceived as compromising the integrity of the research enterprise.

There are many research needs identified by Aboriginal communities – environmental degradation, epidemic health threats, culturally-appropriate economic development to name a few. Although Aboriginal participation in higher education is rising and bicultural scholars are emerging, the numbers of science specialists is still small. The relatively small size of the Aboriginal population, located within a larger society and interacting with it on many fronts, dictates a continuing need for intercultural knowledge exchanges. It is essential that the criteria for ethical intercultural research be developed and distributed.

INITIATIVES TO DEVELOP CODES OF ETHICS FOR ABORIGINAL RESEARCH

Ethical guidelines for Aboriginal research developed by various agencies over the past 15 years provide substantial guidance for principles and practices which have wide support among Aboriginal Peoples as well as in the broader research community.

The most comprehensive set of Aboriginal-specific guidelines is found in the report of a seminar convened in 2000 by resolution of the United Nations Commission on Human Rights. The Report of the Seminar on the Draft Principles and Guidelines for the Protection of the Heritage of Indigenous People treats research ethics as one aspect of protecting Indigenous heritage. It assumes that such protection “should be based broadly on the principle of self-determination, which includes the right of indigenous peoples to maintain and develop their own cultures and knowledge systems, and forms of social organization.”²⁴ Also in the international sphere, the Inuit Circumpolar Conference (ICC) has produced research guidelines.²⁵

In Canada, RCAP published Ethical Guidelines for Research.²⁶ The guidelines applied in the Commission’s extensive research program and have been widely referred to in subsequent years. The current Tri-Council Policy Statement refers researchers to the guidelines published by RCAP, ICC and the Association of Canadian Universities for Northern Studies.²⁷ In 2002, the Strategic Grants Directorate of the Social Sciences and Humanities Research Council distributed an open invitation to those interested in Aboriginal research to participate in a dialogue on establishing priorities and guidelines for a targeted funding program. The three granting councils have established a Panel on Research Ethics (PRE) to work on updating the TCPS. The PRE recognized that there are significant issues relating to ethics of Aboriginal research and actively sought nominees with Aboriginal research expertise to fill a position on the panel as of the summer of 2003.²⁸

Other initiatives have been taken at local and regional levels. The Kahnawake Schools Diabetes Prevention Project adopted the KSDPP Code of Research Ethics²⁹ to guide collaboration between the Mohawk community of Kahnawake, community-based researchers and academic institutions. In 1999, the Grand Council of the Mi’kmaq ratified a Mi’kmaq Ethics Watch. It sets out Principles and Guidelines for Researchers Conducting Research With and/or Among Mi’kmaq People.³⁰ The University of Victoria

has established an ethics review process to accommodate First Nations ethical standards.³¹

Concern about balancing the risks and benefits of research affecting communities and individuals is not confined to research among Aboriginal Peoples, but the best-developed and best-thought-out guidelines relate to Aboriginal communities. Charles Weijer, a bio-ethicist at Dalhousie University examined 16 of these documents written by and for Aboriginal Peoples internationally, including Canada, Australia and United States. Weijer identified five major themes running through the documents.

1. Consultation with the community when developing research protocols and keeping them informed during implementation.
2. Informed consent from community leaders prior to approaching individuals, although the community right of withdrawal was generally not addressed in the documents.
3. Community involvement in conducting the research and transfer of skills and expertise to the community.
4. Access to data and samples is contentious and not always mentioned in guidelines. Community consent to additional use of samples beyond the original project and agreement on storage and subsequent destruction of samples should be required.
5. Advance drafts of research reports should be distributed to the community to identify community views. Community rights to modify the report vary.³²

Canadian-specific guidelines emphasize participation of Aboriginal groups and communities as full partners in the research enterprise.³³ Where the community is a geographical entity with local governance structures, the authority to give community consent may logically reside with the local government. The Kahnawake Schools Diabetes Prevention Project set up a structure for approval that involves agencies mandated by the Mohawk Council of Kahnawake, a community advisory committee, and local health and education systems working in collaboration with university-based researchers. Project implementation and distribution of results requires approval of all the project partners. Reports cannot be vetoed by any one partner, but the dissenter must have the option of presenting alternative positions in oral or written communications.³⁴

University of Victoria guidelines apply to research undertaken in Indigenous Governance Programs and are complementary to the university's policy on Human Ethics in Research. They are to be applied in any

research that "has effects on or could potentially affect Indigenous people." Where there are no identifiable persons or groups to give informed consent, then an Indigenous mentor/consultation group will be established for areas where Indigenous public information/knowledge is cited.³⁵

The Mi'kmaq protocol takes yet a different approach to involving community. The Mi'kmaq Ethics Watch was adopted by the Grand Council of Mi'kmaq to assert the responsibility and authority of Mi'kmaq People as guardians and interpreters of their culture and knowledge system. The protocol applies to "any research/study or inquiry into collective Mi'kmaq knowledge, culture, arts, or spirituality." It establishes a centralized location and format for reviewing applications to conduct research, but assigns primary responsibility for monitoring research within each community. There is a strong element of informing communities of their rights and supporting them in exercising their responsibilities.³⁶

The First Nations and Inuit Regional Longitudinal Health Survey (RHS), an initiative funded by Health Canada to gather national data on First Nations and Inuit health, is another site of negotiation for Aboriginal participation as partners in research. Survey data on the Aboriginal population comparable to data collected on the general Canadian population has varied from incomplete to non-existent. General surveys such as the National Longitudinal Survey of Children and Youth have not included on-reserve samples. Significant numbers of First Nations reserve communities declined to participate in the 1991 and 2001 national Census and related Aboriginal Peoples Surveys that sought more detailed information on Aboriginal Peoples. Health Canada data on medical services on-reserve provide disease and treatment statistics, but not the basis for planning to promote health of the population.

To develop a more complete picture of population health, Health Canada entered into negotiations with representative First Nations and Inuit organizations to partner in data collection in a Canada-wide sample survey on health in 1997. Regional organizations endorsed the survey, with conditions attached to their participation. There were many positive results. Regional organizations took responsibility for administering the survey instruments. They were able to add questions relevant to their own communities in the process of instrument construction. Response at the community and individual level was very high. Appropriate expertise in survey design and analysis was engaged in the regions.

Tensions between government and First Nations partners developed, however, over control of the data. The RHS National Steering Committee, reporting to the Assembly of First Nations Chiefs Committee on Health, adopted protocols to recognize collective ownership of data generated by the RHS. Community level data, including individual records, are not released without explicit permission of community authorities. Community data that is brought together at the regional level is released only with permission of the regional authority. The First Nations Information Governance Committee, mandated by Assembly of First Nations chiefs, makes decisions about the release of analysis and reports produced nationally. Publications developed using the data are similarly subject to review and pre-release approval.

Decisions on control of RHS data are seen as setting benchmarks for partnerships in research. They have generated public discussion that is elaborated on in papers prepared for the National Aboriginal Health Organization (NAHO)³⁷ and the First Nations Statistical Institute.³⁸ The latter is an emerging organization slated to receive its mandate as one part of a legislative package brought forward in 2003 by the Minister of Indian Affairs.³⁹ The suite of legislation establishing fiscal and management institutions serving Indian bands has yet to complete passage through Parliament.

Of particular interest for this discussion of research ethics are the principles of ownership, control, access, and possession (OCAP) clearly set out by the RHS Steering Committee to guide decisions on the use of RHS data. The principles assert: collective ownership by First Nations communities of information about themselves and their members; authority to designate who controls or makes decisions about research affecting them; criteria for access to information about themselves held outside the community and management of access to information held by communities or their agents; and possession of actual records by themselves or their designated agents.⁴⁰

Government agencies have been less than satisfied with the limitations on access imposed by the RHS National Steering Committee under the OCAP formula. They argue that maximum social benefit of publicly-funded research requires open access to data with the usual provisions for protecting the privacy of individual respondents. There are visible benefits from First Nations endorsement of the RHS in terms of response, efficiency and quality of results. Despite

the differences in position between First Nations and government parties, a second survey was undertaken in partnership in 2002 as part of a longitudinal research agenda.

FROM GUIDELINES TO GOVERNANCE

The discussion on ethics of Aboriginal research over the past decade has clearly demonstrated that more appropriate and enforceable protection of Aboriginal Peoples' interests in research activities is required. Aboriginal Peoples are wary, however, of regulations that seek to include them as an addendum to protocols based on western assumptions about the construction and distribution of knowledge. This section proposes some principles flowing from the previous discussion which could guide the development of appropriate ethical regimes.

Creating Knowledge – An Aboriginal Right

Aboriginal Peoples in Canada enjoy Constitutional protection of rights to maintain their identity and participate as collectives in Canadian society. Creating and sharing knowledge that authentically represents who you are and how you understand the world is integral to the survival of a people's identity. The Royal Commission on Aboriginal Peoples, in its analysis of the foundations and exercise of self-government, proposed that "all matters that are of vital concern to the life and welfare of a particular Aboriginal people, its culture and identity" fall within the core of Aboriginal jurisdiction.⁴¹ The Government of Canada has acknowledged the inherent right of self-government, although the substance of the right has not been defined. This leads to the first principle in devising an ethics regime for Aboriginal research.

Principle 1:

Aboriginal Peoples have an inherent right to participate as principals or partners in research that generates knowledge affecting their culture, identity and well-being. This right is protected by the Canadian Constitution and extends beyond the interests that other groups affected by research might have.

Fiduciary Obligations

The restricted capacity of Aboriginal nations and communities to protect their interests and rights in

face of more powerful governments and institutions has led to case law defining fiduciary obligations of Canadian governments. A duty to consult, which could affect how research is conducted, has been recognized in decisions of the British Columbia Court of Appeal. NAHO is currently preparing a paper exploring related issues in Federal Government Fiduciary Obligations to Aboriginal Peoples and Health.⁴²

Principle 2:

The Government of Canada has a fiduciary obligation to guard against infringement of Aboriginal rights in research activities, particularly in institutions and activities for which it is responsible. The appropriateness of particular safeguards must be endorsed by Aboriginal Peoples through their representative organizations.

Diversity of Aboriginal Cultures

In the speech from the throne Sept. 30, 2002, Governor General Adrienne Clarkson announced the Government of Canada's intent to "work with provinces to implement a national system for the governance of research involving humans, including national research ethics and standards." Interministerial discussions on governance of research involving human subjects are already underway, led by Health Canada.⁴³ Review of research ethics by the three research granting councils will take on new urgency to influence the direction of national legislation and accompanying regulations. Ethical codes developed by Aboriginal Peoples recognize the diversity of Aboriginal communities and the primacy of community authority in deciding what matters are appropriate for research, the protocols to be respected, and how resulting knowledge should be distributed.⁴⁴

The situation of the Métis deserves specific attention. Although they are recognized in the Constitution as one of the Aboriginal Peoples of Canada, they are excluded from federal and most provincial legislation protecting their Aboriginal rights and access to culturally-specific services. They generally lack resources to develop organizational and governance infrastructure and to conduct or partner in research undertakings. A search for examples of community-based research protocols did not turn up examples of Métis-specific documents.

Principle 3:

Action by the Government of Canada to establish ethical standards of research should strike a balance between regulations that restrict infringement of Aboriginal rights and those that respect the primacy of ethical codes originating in affected communities, including Métis communities.

The Scope of Ethics Regimes

Earlier in this paper, I argued that ethics that govern research only on human subjects is too restricted to provide the protections sought by Aboriginal Peoples. The report to the Commission on Human Rights from the seminar on draft principles and guidelines for the protection of the heritage of Indigenous People provides a useful model for defining the scope of ethical regulation. The report proposes that heritage broadly defined should be the object of protective measures.

Principle 4:

Ethical regulation of research affecting Aboriginal Peoples should include protection for "all knowledge, languages, territories, material objects, literary or artistic creations pertaining to a particular Aboriginal Peoples, including objects and forms of expression which may be created or rediscovered in the future based upon their traditions" as cited in emerging international norms.

Harmonization of Ethical Protection and Intellectual Property Law

A study of intellectual property and Aboriginal Peoples sponsored by Indian and Northern Affairs Canada underlines the inadequacy and inappropriateness of existing intellectual property regimes in protecting traditional Aboriginal knowledge. National and international rules governing copyright, trademarks, patents, and licensing procedures consistently conflict with Aboriginal culture norms or are practically inaccessible.⁴⁵ Canadian rules are designed to conform to international standards.

Authority to enact legislation to protect heritage, including intellectual property, should logically be assumed by Aboriginal governments as they emerge. However, it appears that new governments established under the *Nunavut Act*⁴⁶ and the Nisga'a Final Agreement sidestep a number of issues. The Nunavut government has authority to legislate in the areas of prop-

erty, language, and matters of a local or private nature. It is unclear whether the intangible dimensions of property would fall under its jurisdiction. In the Nisga'a Final Agreement, authority over intellectual property is specifically addressed:

42. Except as provided for by federal or provincial law, Nisga'a Lisims Government jurisdiction under paragraph 41 to make laws in respect of Nisga'a culture and Nisga'a language does not include jurisdiction to make laws in respect of intellectual property, the official languages of Canada or the prohibition of activities outside of Nisga'a Lands.⁴⁷

The RCAP Report provides a more extensive analysis of issues relating to the protection of Aboriginal heritage and intellectual property.⁴⁸ The principle proposed here echoes RCAP recommendation 3.6.7.

Principle 5:

*"The federal government, in collaboration with Aboriginal peoples, [should] review its legislation on the protection of intellectual property to ensure that Aboriginal interests and perspectives, in particular collective interests, are adequately protected."*⁴⁹

Administrative infrastructure

Implementation of an ethics regime in Aboriginal research requires more than the clear statement of principles. Legislation at best sets out boundaries for protection of heritage rights. As noted earlier, the administration of existing guidelines is in the hands of research ethics boards (REBs) located in universities and research institutes from which Aboriginal communities are generally distant socially and culturally. The *Indian Act*, which sets parameters for program funding for registered Indians, makes no provision to support research administration or ethics enforcement in its administrative regimes.

The Mi'kmaw of Nova Scotia and the Mohawks of Kahnawake have created their own administrative structures to implement community codes of ethics. There are undoubtedly other Aboriginal communities that have devised creative responses to the challenges described in this paper. Equitable benefit from legislation and regulations will require investment in administrative structures to monitor compliance with ethical processes. Exploration of the American experience with research reviews could

prove useful in this regard. The U.S. Department of Health and Human Services' Indian Health Service (IHS) has a national Institutional Review Board (IRB) plus 13 regional-level IRBs. University-based projects are reviewed by their own institutional review boards. Then, they go to the IHS regional body for approval of area-specific protocols. In some regions and projects, tribal approval at the local level is required before the regional or national level IRB gives approval.⁵⁰

In its submission to Health Canada on Governance of Research Involving Human Subjects, NAHO recommended the creation of a system of Aboriginal research ethics boards (AREBs) to address local, regional and national Aboriginal concerns. The brief further recommended that a national committee be formed consisting of Aboriginal experts who would develop ethical standards that could provide a reference point for AREBs and minimum standards for institutional REBs.⁵¹

Principle 6:

Development and implementation of ethical standards for Aboriginal research should be in the hands of Aboriginal Peoples, as experts in devising minimum standards for general application and as majority members on Aboriginal-specific research ethics boards serving local, regional and national communities.

Costs of implementing an ethical regime

Briefs submitted in response to SSHRC's invitation in 2002 noted that establishing the relationships and ground rules for research in Aboriginal communities required time and effort prior to finalizing a research proposal.⁵² Granting councils generally do not fund up-front costs of developing a research plan, thereby placing serious limitations on respectful, that is, ethical research practice in or with Aboriginal communities.

Aboriginal involvement in research to support evidence-based decision-making in service planning is generally not recognized in the administration budgets of Aboriginal communities and organizations. The First Nations and Inuit Regional Longitudinal Health Survey (RHS) is an exception. When given the opportunity to shape the 1997 RHS in accord with their self-defined priorities, Aboriginal communities engaged in the research enterprise with a high degree of efficiency and effectiveness.

Principle 7:

The costs of community consultation, development of research plans, negotiation and implementation of ethical protocols, and skills transfer should be recognized in budget formulas for research grants and project planning whether conducted by researchers internal or external to Aboriginal communities.

Education for Ethical Practice

Ethics of consent, safety and social benefit in research have evolved over decades. Ethical practice is advanced through a combination of institutional regulation, peer monitoring and communication in the venues where researchers meet and confer with one another. Establishing research practices that respect Aboriginal world views, priorities and authority will also be an evolving process.

Aboriginal communities that have taken up the challenge of conducting and monitoring research have promoted a broad base of local involvement in field research, management committees and board governance. By their actions, they have demonstrated that research is too important to be left to a small group of academics, even if the experts are Aboriginal. Aboriginal community researchers, in concert with their peers in graduate schools and universities, are now talking about reinstating Aboriginal research methodologies to explore processes that have been neglected or poorly represented in past research. The terminology used for this process is community control, borrowing the language that has driven parallel moves to assert Aboriginal authority over government institutions, education, health, and social services.

Aboriginal initiative is essential to reform research practice and bring it into conformity with Aboriginal notions of ethical behaviour. Aboriginal assertiveness is already evident in the surge of activity devising community research codes and the demands for effective partnership in major research undertakings. Research granting councils have a complementary role to play in developing and promoting policy guidelines. A few professional associations have begun to formally recognize the legitimacy of Aboriginal-specific protocols. Some universities have adapted their review processes to promote ethical relationships with Aboriginal communities, including communities of interest.

Principle 8:

Responsibility for education of communities and researchers in ethics of Aboriginal research rests with Aboriginal communities and organizations, government funders, granting agencies, professional associations, research institutions, and individual researchers working collaboratively.

CONCLUSION

This paper places the discussion of ethics governing Aboriginal research in the context of cultural world view and the struggle for self-determination as peoples and nations.

Self-determination has been seen as a political goal expressed most notably in self-government that recognizes a degree of autonomy in relation to Canadian state institutions.

The language of self-government has obscured the reality that Aboriginal Peoples are engaged in a struggle to re-establish ethical order in their communities and nations. This order re-affirms fundamental values that are rooted in their traditional construction of reality, sometimes called a world view. Efforts to regain control of education, health, justice, etc. are only in part about the power to govern. They are fundamentally about restoring order to daily living in conformity with ancient and enduring principles that support life.

Aboriginal Peoples are digging deep into their traditional teachings, reviving their ceremonies, and working to conserve their languages. As they take control of community services and institutions, they are proving that traditional teachings offer a sturdy ethical framework for restoring vitality to community life. Aboriginal academics, professionals, service providers, and political leaders are rediscovering and updating traditional values in the practice of education, the arts, health services, justice, and government. They are also challenging the assumptions of research rooted in a scientific world view that clashes with their concepts of reality and right relationships.

It would be wrong to suggest that all Aboriginal Peoples hold traditional world views with the same degree of tenacity. However, applied research, going on spontaneously and autonomously in Aboriginal communities and organizations, is demonstrating that when learning, healing or rehabilitating is aligned with traditional ethics and values, it takes on astounding energy. The leaves of a tree, connected to their vital source, display health and vigour.

The active discussion of research ethics now going on in government and in granting councils opens up an opportunity for Aboriginal Peoples to engage in dialogue on how research can be adapted to achieve social benefit as they define it. The principles proposed in this paper start with an affirmation of the right of Aboriginal Peoples to generate and disseminate knowledge for and about themselves. This is not to say that all dialogue should halt until complex questions about rights and responsibilities are definitively resolved. Starting with such an affirmation simply underlines that governance of research touches on fundamental issues of Aboriginal culture, identity and well-being.

Establishing and enforcing ethical practice in Aboriginal research will require a continuing commitment to implementing protective legislation, administrative infrastructure and education of the many participants in research.⁵³ It is my hope that the articulation of issues and principles in this paper will advance the dialogue that is already underway.

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ENDNOTES

1. This paper was commissioned in 2002 by the National Aboriginal Health Organization to assist in developing an organizational position on research ethics. Documentary research and conceptual development were substantially advanced by conversations with NAHO staff, particularly Richard Jock, Yvonne Boyer and Gail McDonald. Analysis and interpretation, errors and omissions are entirely the responsibility of the author.
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