9 A Two-Eyed Seeing Approach
  To Research Ethics Review:
  An Indigenous Perspective

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The landscape for research ethics review in Canada is a challenging one that is constantly changing. With the development and implementation of various policies and guidelines, especially in research involving Aboriginal peoples,[1] there appears to be no end to the ethics review process. To complicate things further, the Province of Newfoundland and Labrador has recently passed legislation requiring that all health research studies conducted in that province undergo provincial research-ethics review, above and beyond any review requirements already in place. These multiple layers and stages of review are likely to leave researchers confused regarding what they need to do in order to fully meet requirements at all levels.

This chapter provides a brief history of the development of guidelines and policies for research involving Aboriginal people, as well as the circumstances that necessitated those changes. This includes a review of Aboriginal and non-Aboriginal ethics review and a discussion about the complexities of community consent and research resistance within Aboriginal communities themselves. Following that review, I argue that using a two-eyed seeing model,[2] which incorporates both Aboriginal and Western principles of research ethics, for research involving Aboriginal people will yield better outcomes both for the researchers and for the communities being studied. Given that Canada is one of the leading countries in this area of study, it is of great value to determine the best possible way to conduct research ethics review. This is especially true considering that the Province of Newfoundland and Labrador is currently undergoing major policy and legislative changes[3] that are designed to contribute to a greater understanding of ways to streamline the cumbersome process for researchers conducting research

involving Aboriginal people, while still assuring adequate protection for the participants.

Research Involving Aboriginal Peoples in Canada

Context

This section provides a brief history of research involving Aboriginal people in Canada by highlighting some of the key assumptions that underpin policies in this country. This is followed by a chronological account of the development of research ethics policies and guidelines in Canada for research involving Aboriginal people. This section will introduce the problematic assumptions that underlie how research involving Aboriginal peoples has typically been conducted, and then provide an overview of recent efforts within Canada to recognize and address these issues.

The history of research with Aboriginal people in Canada mirrors that of Indigenous people worldwide: research has traditionally been done *on* the population due to governmental and cultural assimilation or segregation policies, exoticization of Aboriginal ways of life, and misappropriation of their cultures (Smith, 1999; Battiste and Henderson, 2000). With scant attention having been paid to the role of Aboriginal people themselves, policymakers have only recently developed guidelines for the ethical conduct of research that actually regards Aboriginal perspectives and goals for research as central concerns.

During the past two decades, the ethical governance of research involving Aboriginal peoples has garnered international, national, provincial, and local attention (Kaufert et al., 2004), with a particular focus on Aboriginal ethics and the effects of health research on these social groups. This type of interest in health research originally grew primarily from genetic research with collectivities (groups of people who share a genetic similarity). Together, concerns regarding health research involving collectivities and Aboriginal people have fuelled much debate regarding the importance of research involving Aboriginal peoples and the ethical concerns associated with doing so.

Historically, four key assumptions contributed to the questionable treatment of Aboriginal peoples in research, and each of these remains evident in government policies. The first assumption is that Aboriginal peoples are inferior and are not capable of self-governing. The second is that treaties are merely "a form of bureaucratic memorandum

of understanding, to be acknowledged frequently, but ignored often," according to the Royal Commission on Aboriginal Peoples (RCAP; Indian and Northern Affairs, 1996: 4). Third, policies have assumed that actions deemed to be of potential benefit to Aboriginal communities do not require consent or consultation by these communities. The fourth assumption is that non-Aboriginal values are sufficient in driving individual or community development, without the presence of Aboriginal values. Many scholars have described these false assumptions in detail (e.g., Smith, 1999; Battiste and Henderson, 2000; Gegeo and Watson-Gegeo, 2001; Ermine, 1995), and the Royal Commission on Aboriginal Peoples itself summarizes these assumptions in Part II of its 1996 report (Indian and Northern Affairs, 1996). While these assumptions have gradually become less explicit through the evolution of policies, they do continue to "significantly underpin the institutions that drive and constrain the federal Aboriginal policy process" (4).

Criticism of these assumptions within the literature on Indigenous ethics and policy has significantly shaped the formation of new guidelines for health research involving Aboriginal peoples in Canada, primarily through the work of the Royal Commission on Aboriginal Peoples. These efforts resulted in the creation of the Institute for Aboriginal Peoples Health(IAPH), as one of the arms of the Canadian Institutes of Health Research (CIHR), and its Aboriginal Capacity and Development Research Environments (ACADRE)[4] centres, and culminated in the *CIHR Guidelines for Health Research Involving Aboriginal Peoples* (2007). More than 350 research projects were commissioned through the Royal Commission on Aboriginal Peoples, including research on the ethics of research involving Aboriginal peoples, and research on respecting the culture, language, knowledge, and values of Aboriginal peoples. According to the Royal Commission on Aboriginal Peoples, this renewed attention reflected the view that "Aboriginal peoples have distinctive perspectives and understandings deriving from their cultures and histories and embodied in Aboriginal languages [and therefore] research that has Aboriginal experience as its subject matter must reflect these perspectives and understandings"[5] (Indian and Northern Affairs, 1996: 2). The important contribution of the Royal Commission on Aboriginal Peoples with respect to research involving Aboriginal peoples, then, was the assertion that a blanket approach to research ethics and health services is insufficient – that the particular needs and cultural qualities of different peoples necessitate the formulation of specific and unique guidelines for research involving Aboriginal peoples.

In 2001, Canada's prime minister established the Commission on the Future of Health Care in Canada. The mandate was to review Medicare (Canada's publicly funded universal health insurance system) and consult with Canadians about the future of health and the health care system. Led by Roy Romanow (a former premier of Saskatchewan), the Commission released *Building on Values: The Future of Health Care in Canada* in 2002 – the *Romanov Report* (Commission on the Future of Health Care in Canada and Roy J. Romanow, 2002). As the Royal Commission on Aboriginal Peoples did in 1996, the *Romanow Report* identified the need for restructuring health research involving Aboriginal peoples. Importantly, the *Romanow Report* stressed the need for community input and collaboration through holistic approaches as the means to accurately reflect the needs of the community.

Policies

The recommendations of the Commission on the Future of Health Care in Canada coincided with the movement towards self-determination by Aboriginal peoples in Canada and elsewhere, which, along with the subsequent rise in research on community health in Aboriginal contexts, led many Aboriginal communities to develop their own ethics review processes and procedures. According to Iara Guerriero (personal communication with W.C. van den Hoonaard, Oct. 2011), Canada has some 33 ethics guidelines that outline the nature of ethical research involving Aboriginal peoples. One of the most significant developments was produced by the Steering Committee of the First Nations Regional Longitudinal Health Survey, which, in conjunction with the First Nations Centre at the National Aboriginal Health Organization (NAHO), developed principles of Ownership, Control, Access, and Possession (OCAP) of data[6] as "an expression of self-determination in research" (Schnarch, 2004: 81). These principles, which incorporate themes advocated by First Nations in Canada regarding research,[7] were very clearly "a political response to tenacious colonial approaches to research and information management" (80). Identifying the principles as "a way out of the muddle of contemporary Aboriginal research and the ethical dilemmas that characterize it" (80), Schnarch argued that researchers should become aware of these new principles and integrate them into their research

Canada's *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 1)*, developed by the Tri-Council Working

Group, included a section about research involving collectivities, but the final 1998 policy statement did not (CIHR et al., 1998). In its place was section 6, a temporary "place holder" for guidelines for research involving Aboriginal peoples. The preface noted that section 6 had undergone insufficient consultation at the time of publication, such that it was premature to establish policy for ethics involving Aboriginal peoples. Section 6 was to be developed through discussions and consultations with Aboriginal peoples.

In 2003, the Interagency Panel on Research Ethics (PRE), as the trustee of Canada's *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, was committed to revising the *Statement*, including section 6.[8] Meanwhile, drawing on the OCAP principles, the ACADRE Centres, in collaboration with researchers and Aboriginal communities, the Canadian Institutes of Health Research ethics office, and the CIHR Institute of Aboriginal Peoples' Health, conducted background research with the goal of creating a set of guidelines for research involving Aboriginal peoples (PRE, 2002).[9] From that process, the Canadian Institutes of Health Research created an external advisory body called the Aboriginal Ethics Working Group in 2004 (CIHR et al., 1998). That group then collaborated with the ACADRE Centres, Aboriginal communities, and scholars in Indigenous studies, anthropology, ethics, law, medicine, public health, and the natural and social sciences (CIHR et al., 1998), resulting in the development of the 2007 *CIHR Guidelines for Health Research Involving Aboriginal People*. These *Guidelines* were officially implemented by the Canadian Institutes of Health Research in 2009.

Less than a year later, in 2010, the three federal research agencies (Canadian Institutes for Health Research, the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council of Canada, collectively known as the "Tri-Council") released its new draft of the second edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (*TCPS 2)*. This document replaced the placeholder in the original *TCPS* with a full chapter about research involving First Nations, Inuit, and Métis people and communities.[10]

Principles of Aboriginal and Non-Aboriginal Ethics

There are many ways in which Aboriginal and non-Aboriginal perspectives differ with regard not only to how research is conducted but also

how proposed research is assessed, and how these differences lead to issues that must be addressed in order for research in Aboriginal communities to be done in an appropriate manner. Combining all Aboriginal and non-Aboriginal principles together is ill-advised, especially considering the obvious variations, deviations, and overlaps that exist within each group. However, to get a clear idea of the fundamental differences between these groups with respect to how they understand ethics in research, it is necessary to juxtapose the basis of these principles.

Non-Aboriginal notions of ethics, as developed within the biomedical framework, focus primarily on the individual (Beauchamp and Childress, 1994). The cornerstone principles of bioethics are autonomy (self-determination), non-maleficence (no harm), beneficence (obligation to do good), and justice (fair treatment and privacy). The biomedical framework sees the individual "self" in a way that is spatially and temporally different from conceptualizations of the self that exist within Aboriginal frameworks. In traditional Aboriginal ways, the self is not bound by the individual. Rather, it includes past and future generations in the community. The Aboriginal notion of the "self" constitutes a sacred space, with interconnected relationships among living humans and other spiritual entities, the land, ancestors, and animals; there is no separation of the individual from these other elements (Ellerby et al., 2000). Non-Aboriginal concepts of "self" give little or no regard to such relationships.

The focus on "individual ethics" is therefore culturally inappropriate in most Aboriginal contexts. Consequently, it is necessary "to view contemporary ethical standards for Aboriginal health research within a broader historical context and through both Aboriginal and western scientific perspectives" (CIHR, 2007: 10). Such integration of two world views (or more, considering the possible existence of differences *within* the two categories) is reflected in Marshall's understanding of two-eyed seeing (Bartlett and Marshall, 2010), and supports the notion that considering these two world views yields greater understanding of and outcomes for those involved. With these issues in mind, researchers must alter their methodologies to reflect a holistic undertaking that reflects Aboriginal perspectives – rather than the typical individual-centred approach – and they may also have to re-evaluate their understanding of concepts like *ownership* and *sharing*. Even the ethics review itself must be altered in order to accommodate how this process is understood and perceived by Aboriginal peoples.

Formulating research ethics that suit a particular group (e.g., Aboriginal peoples) involves establishing research methodologies that reflect (or at least do not contradict) local cultural norms and community values, obviating the norms and values held by the researcher, regulator, research institution, or participant (Weaver, 1997). This approach does not necessarily require complete changes to research methods – it can be as simple as engaging in an interview instead of survey research. As Renee Louis (2007) states, "Indigenous methodologies can invigorate and stimulate geographical theories and scholarship while strengthening Indigenous people's identities and supporting their efforts to achieve intellectual self-determination" (137). Thus, a holistic research approach is more favourable in Aboriginal methodologies (Ermine, 1995; Smith, 1999; Battiste and Henderson, 2000; Atleo, 2004; Porsanger, 1999), in contrast to many Western methodologies that have the "tendency to compartmentalize experience and thus assume that some parts have no relationship to other parts" (Atleo, 2004: xi).

In addition to addressing how research is conducted, researchers must also consider how Aboriginal cultural values and concerns apply to the ownership and sharing of data, and how this differs from the traditional ways in which data are conceptualized and handled. The importance of protecting traditional knowledge stems from issues of fundamental justice and of protecting and preserving culture (Smith, 1999). Protection of Aboriginal people is necessary in part because of the misuse and misappropriation of traditional knowledge by mainstream interests (Smith, 1999). To address critical issues of colonialism and to avoid both misrepresentation and marginalization of Aboriginal ways of knowing, Aboriginal communities have developed Indigenous knowledge frameworks (Battiste and Henderson, 2000; Smith, 1999). The language of ethics coming from Aboriginal peoples, scholars working in the field, and from Aboriginal communities, indicates the existence of conflicting interpretations of ethics that are based in different world views (Smith, 1999; Battiste and Henderson, 2000; Bull, 2010).

There is a general mistrust of research and researchers in Aboriginal communities, which can be especially problematic considering that trust is a key element of research. A researcher entering an Aboriginal community for the first time can expect trust to be absent and hard to earn, thanks mostly to a long history of political oppression. To rebuild this trust, researchers need to create relationships on a foundation of respect, relevance, responsibility, and reciprocity (Bull, 2010). While these fundamental notions of respect are not unique to Aboriginal

value systems, all of them have been seriously lacking in mainstream research practices and are particularly important in the case of Aboriginal peoples. Indeed, values of respect, relevance, responsibility, reciprocity, and protection do not contradict the applied principles in conventional non-Aboriginal ethical frameworks, but this framework undergoes a shift when applied to research in Aboriginal communities.

In terms of developing trust, researchers must remember that political and economic oppression cannot be separated from issues of research. As Joseph Kaufert et al. (2004) remind us, "Research should focus on locally relevant problems, or ensure that there be a commitment to community-based capacity building and the generation of local knowledge" (25).

The lack of understanding by researchers (and by non-Aboriginal ethics review committees) of the historical processes of oppression and injustice "represent[s] a fundamental shift in the philosophical basis influencing the guidelines" in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Kaufert et al., 2004: 44).

Research Resistance

This section highlights the necessity for decolonization in research involving Aboriginal people and research resistance from within Aboriginal communities themselves.

To address the numerous issues that arise form differences in perspectives and values, Gillam and Pyett (2003) propose a complementary process where multifocused frameworks and documents are used to express key points of convergence and disconnection between Aboriginal communities and non-Aboriginal ethics review committees, including Research Ethics Boards (REBs). However, resistance to non-Aboriginal research approaches and their ethical suppositions began much earlier, in the 1970s, when Aboriginal scholars and writers began to criticize the imposition of research on Aboriginal peoples (Deloria, 1991). Aboriginal scholars provided important critiques, highlighting the problem that Western research conducted on Aboriginal communities invalidated Aboriginal knowledge, leading to a disconnect in "traditional teachings, spirituality, land, family, community, spiritual leaders [and] medicine people" (Absolon and Willett, 2004: 9). The process of decolonization does not merely include the rejection of Western scientism – it is also about "centering our concerns and world views and coming to know and understand theory and research from our own

perspectives and for our own purposes" (Smith, 1999: 39). The concept of *pluralism* is an essential dimension in Aboriginal ethics wherein the diversity among and within Aboriginal communities makes it difficult to develop widely applicable ethical decision-making processes. As Jonathan Ellerby et al. (2000) aver, "Despite some shared beliefs, each cultural group must be treated with respect and an understanding of inherent diversity" (70).

Scrutinizing the purpose of the research itself is a significant aspect of the movement to decolonize research involving Aboriginal peoples. Westerners, particularly anthropologists, have primarily conducted research that is of an exotic (and essentializing) nature, at the expense of research that might have improved the well-being of Aboriginal people. Much of the research conducted in Aboriginal communities historically has had little or no positive impact on the health or social well-being of those communities, and even tends to paint Aboriginal people as inferior by focusing more on perceived deficits rather than on the strengths of people or communities. Aboriginal communities are now understandably cautious, and are challenging the research community to be cognizant of research practices that are based on exploitation, racism, ethnocentricity, and harmfulness (Smith, 1999; Battiste and Henderson, 2000): "Homogenisation, exoticisation, and misrepresentation are an interrelated cluster of historical contexts that shape the meaning of 'ethical' research and define contemporary strategies for ownership, control, access, and protection" (Brunger and Bull, 2011: 133). As the CIHR Guidelines for Health Research Involving Aboriginal People remind us, "[All] parties should understand that all research involving Indigenous knowledge, even when not commercially motivated, has the potential to be commercialized and possibly misappropriated when publication occurs" (CIHR, 2007: 23).

Political climates in and among Aboriginal communities cannot be separated from ethical and epistemological perspectives. Ethical frameworks that are meant to function in Aboriginal contexts must incorporate Aboriginal values and must disallow the forced Western imposition that has characterized past practice (Scott and Receveur, 1995; Brant-Castellano, 2004). To accomplish this, researchers must take cultural norms and values into account in research design and methodology. Yet, making predictions based on general tendencies can be problematic, as well, due to the variability that exists not only between groups but also within them. The importance of attending to cultural values and beliefs is not for predictive value, but rather to offer a critique of

the degree of generalizability of established cultural norms (e.g., the importance of individualism in non-Aboriginal bioethics systems) to all contexts.

Some of the concerns expressed by Aboriginal people are rooted in their own values and ethics systems, which in some cases differ greatly from Western views. Nonetheless, many Aboriginal values, ethics, and epistemologies are parallel to those of the Western world, such that the goals of Western approaches to research ethics are not necessarily incompatible with Aboriginal understandings of ethical research. The disconnection that arises relates more to the ideologies and theories about *how* to conduct ethical research and the actual *processes* of conducting ethical research. The most notable example of this is informed consent. In theory, informed consent is an ongoing process, rather than the single act of signing a consent form. However, it is not uncommon for researchers to reduce the process of informed consent to the one-time signing of a consent form. This problem, rooted in the discrepancy between what consent is intended to represent and how it is actually handled within research, is not unique to research with Aboriginal people.

Community-Driven Ethics Review

As a natural extension of self-determination, Aboriginal communities are (re)claiming control over programs and services; as a result, research ethics and governance have become priorities in Aboriginal communities. This section explains the complexities of community consent and highlights the importance of community relevance in research involving Aboriginal people. Aboriginal communities have developed highly effective community consent contracts and ethics review systems and procedures. The Code of Ethics of the Kahnawáke Schools Diabetes Prevention Project (1996) and the *Manitoulin Island Guidelines for Ethical Research* (2001) provide two of the best examples. By controlling their own research agendas, Aboriginal people are able to use their spiritual and philosophical foundations to guide how research is done (Smith, 1999). This does not mean that only Aboriginal people can conduct Aboriginal research, but that they are intent on playing a greater role in how that research is conducted. Communities that are actively engaged in developing research priorities have a greater sense of involvement, ownership, and accomplishment overall.[11]

Community Consent

These community-driven research agreements have both shaped and been shaped by academic writings on the very issue of collective consent to research. Where an entire community is at risk, even if only a few people from the community participate, individual consent is necessary but not sufficient (Greely, 1997; Weijer et al., 1999; Burgess and Brunger, 2000; Kaufert et al., 2004). According to Henry Greely (1997), "It is the group's collective autonomy that is challenged if researchers, with informed consent of only a few individuals in the group, can probe for information about the whole group" (1431). Likewise, health research can present genuine risks for socially identifiable populations, further indicating that individual informed consent is not sufficient for ethical research involving Aboriginal peoples (Brunger and Weijer, 2007; Weijer et al., 1999; Kaufert et al., 1999).

   The approach to gaining community consent in Aboriginal communities is similar to the process of conducting research in a school environment. Researchers are frequently required to get approval from the school board, principal, teacher(s) of class(es), parents of children participating, and finally the children themselves. Likewise, consent within an Aboriginal community may involve getting different forms of consent that go beyond just the consent of the study participants. Yet, the kind of approach described above does not always articulate the complex realities of authority structures within Aboriginal communities. The lines of accountability are not obvious, especially if no group of elders or a politically appointed council exists. At the same time, one must consider how the individual interests of those who might be in a position to offer consent for the community may conflict with research beneficial to that community. Consider the scenario of a researcher examining Aboriginal chiefs' perspectives on, and their treatment of women. Community members may be eager to participate in such a study, but how would "community consent" be obtained? It is unlikely that chiefs would agree to this proposed research given that they likely perceive they are being targeted by it. For this reason, Aboriginal communities are implementing research governance structures that are independent of political governance.

   A common issue raised in relation to community consent is finding the appropriate authority. Organizations in every province are in place to provide assistance, as is recognized in the CIHR Guidelines for Health Research Involving Aboriginal People: "The determination of a

community's best interests regarding knowledge may be the responsibility of the family, the band (several families combined), the tribe (several bands combined), or the confederacy (several tribes together)" (CIHR, 2007: 15). This discourse is specific to First Nations, but similar structures can exist in other Aboriginal communities, many of which have multiple structures of authority, meaning that discussion and negotiation is necessary in order to identify the most appropriate body for any given project. Researchers should not "assume that one political body has complete authority" (16), as is typical in non-Aboriginal systems. Negotiating these political relations is necessary but difficult: such relationships and structures differ not only from community to community, but also over time.

When an appointed authority and a cohesive community are in place, researchers must collaborate with that community to ensure that the research goals are appropriate, that they explain and justify potential harms and benefits, and that methods are congruent with the community needs and expectations (Greely, 1997; Bull, 2010; Weijer et al., 1999; Burgess and Brunger, 2000). Brunger and Bull (2011) make the point that "speaking on behalf of a group raises problems of representation and authority given intra-group politics and power differentials, even within a relatively cohesive community" (136). Individual consent should be obtained only after this community-level consultation begins. The importance of community consent and collective decision-making in general does not erode individual autonomy or the requirement for individual informed consent in these situations.

Conceptual and operational problems plague attempts to define *community* and *community consent*, but, according to Joseph Kaufert and his colleagues (2004), "this debate also reflects a general and continuing lack of consensus over their meaning" (13). In the context of Aboriginal research, community "constitutes a structure of support mechanisms that includes an individual's personal responsibility for the collective, and reciprocally, the collective's concern for individual existence" (CIHR, 2007: 15). It is also important to recognize that many Aboriginal communities have "distinct political, legal, and cultural governance structures that have political legitimacy and that support their jurisdictional and decision-making authority on a broad spectrum of issues" (16). Community guidelines, according to Kaufert et al. (2004), "tend to emphasize the uniqueness of each community and hence, the need for approval of research studies that could have implications for the community as a whole" (16). Thus, researchers have an "obligation to learn

about the local customs of an Aboriginal community" (CIHR, 2007: 24) and abide by these customs every time.

Community Relevance

Community relevance in Aboriginal research is part of the ethics review process from the community perspective. REBs should not be responsible for connecting the researcher with the community. Instead, the onus is on the researcher to establish this relationship. Communities have for many years been giving research information and data to researchers who have used that information *only* for the researcher's benefit, sometimes only in pursuit of academic degrees. Consider a small Aboriginal community with increasing rates of suicide. Such a community would not likely be open to researchers interested in the prevalence of suicide, but will welcome those who will be exploring the issue of access to mental health services and care for those suffering from suicidal ideation.

Though it may be the case that some community members have a misconception of what research can and cannot do, they ought to realize that the concept of *benefit* should not be taken to mean benefits in specific health outcomes. Some research will prioritize social or economic benefits as being valuable. These types of benefits range from discussing intervention- or program-based conclusions to offering to assist in building local capacity. Community members generally understand that not all research will have direct or immediate benefits. Although researchers cannot promise such things, indirect benefits may come to the community being studied; these may include "financial or other direct remuneration to participants or to community cause; clinical outcomes for individuals; evidence to support a local initiative to secure program funds; employment for research assistants; and workshops or trainings sessions in the community for capacity building" (Brunger and Bull, 2011: 132).

Ethical Space and Two-Eyed Seeing

Ethical space refers to understanding the strengths and challenges of bringing together different ways of knowing and applying it to practice. The concept, originally coined by Roger Poole (1972), was further developed by Willie Ermine (1995) into a theoretical framework with Western and Aboriginal knowledge relative to research. Ethical

space essentially represents a complicated and abstract realm in which two entities with different intentions can meet. It is unlikely that the community (one of the two entities) will have one united set of intentions and perspectives, so any ethical space will inevitably be complicated at the community level due to conflicting views within and among bands, chiefs, elders, community members, and organizations. Ermine's notion of ethical space helps illuminate the complexities of the researcher–research community relationship.

Part of understanding an Aboriginal ethical space is to understand the role of traditional knowledge and sacred space in research. This is especially pertinent with research specifically examining a sphere of traditional or sacred knowledge; however, it should be applied to all research involving Aboriginal people. As the CIHR Guidelines for Health Research Involving Aboriginal People assert, "Any research involving Aboriginal people will involve the sharing of some cultural knowledge, practices, and/or traditions even when these are not the subject of the study, as they provide necessary context" (CIHR, 2007: 22).

If we consider this abstract space as the meeting point of two world views, it is in that space that the model of two-eyed seeing is evident and valuable. Mik'maq Elder, Albert Marshall (see (Bartlett and Marshall, 2010) submits that seeing the world from Indigenous and Western perspectives yields a more holistic understanding of any given phenomenon. In this case, bringing together principles and practices from Western and Indigenous ethics and ethics review gives a greater understanding of how to implement policies such as the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.*

From Principles to Practice

Research with Aboriginal peoples does not require a complete dismissal of traditional academic research processes. Rather, researchers and communities should work together on the basis of respect for the ethical spaces of all parties, asking continuously, "Is this ethical?" (CIHR, 2007: 17). Achieving this goal requires discussions of the "intentions, values, and assumptions" (17) throughout the duration of the project.

The NunatuKavut (formally the Labrador Métis Nation) is introducing a rigorous community-based research review process. Brunger and Bull (2011) conducted a study in Labrador to find out what should be included in community research-ethics review and identify "whether and how community review should be distinct from the centralized

'institutional' research ethics review that would be the mandate of the Newfoundland and Labrador's … provincial research authority" (127).

The research relationship between Brunger, Bull, and the NunatuKavut community began in 2006 after a workshop about community health research, called "Learning, Listening and Working Together," that was sponsored by the Atlantic Aboriginal Health Research Program. This workshop brought together health workers, community members, and university-based researchers to identify priorities for health research. Two overarching themes emerged: (1) research ethics and (2) the governance of health research involving Aboriginal people. A key outcome of the workshop was the development of the Labrador Aboriginal Health Research Committee (LAHRC).[12] The LAHRC assumed the role of advisory committee for Brunger and Bull's (2011) project and identified key people in the community to be interviewed. These interviews identified several concerns related to benefit sharing,[13] dissemination, and community autonomy: "This cluster of interrelated concerns was understood and discussed as being inextricably connected to the context of ongoing colonization, assimilation, and exoticism" (131).

The issues raised by community members in Labrador echo the concerns mentioned throughout this chapter. By having a community ethics-review system in place, the interests of the local group can be recognized and considered. The policy set out in Newfoundland and Labrador clearly defines the role of ethics review and community review, and serves as a good example of how to streamline the review process for research involving Aboriginal people. There must be clear evidence of acceptable community review before the Health Research Ethics Board (HREB) will approve any research involving Aboriginal people. It is recognized that Aboriginal communities are at different stages of developing research review committees, and not all communities have the capacity to review projects. For this reason, if there is a community authority, there is a requirement to have a community-researcher agreement. If no clear authority structure exists, a community consultation and a letter of support are necessary prior to obtaining HREB approval.

Conclusion

This chapter addresses many of the issues and challenges raised in chapter 9 of the 2010 *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (*TCPS 2*). However, it is not evident in this policy statement how to actually enact its principles. Because the focus

of the *TCPS 2* has shifted to participant involvement and community engagement, it is imperative to determine a way to operationalize these concepts and enact the principles. A common challenge, of course, lies in the fact that any principle-based approach is open to interpretation, may be understood differently by different people, and may be criticized for being unscientific. What is evident is the need to incorporate non-Aboriginal and Aboriginal frameworks using a two-eyed seeing model. The work being done by Brunger et al.[14] in Newfoundland and Labrador will continue to contribute to the body of knowledge about ways to streamline the research-ethics review process and develop a theoretical framework for implementing the principles of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* in Aboriginal settings.

NOTES

1 The term *Aboriginal* is used to refer to Canada's Indigenous peoples – First Nations, Inuit, and Métis. These three groups are recognized by the Constitution Act of Canada, section 35.

2 The Two-Eyed Seeing Model was developed by Mik'maq Elder Albert Marshall (Bartlett and Marshall, 2010). Marshall's development of "Two-Eyed Seeing" teaches us to use the best of both Aboriginal and non-Aboriginal world views to make positive strides forward. He recognizes the substantial value that multiple perspectives give and it is by using multiple perspectives that a better and more holistic understanding is achieved.

3 Since the proclamation of the Health Research Ethics Authority in 2011, all research conducted in the province of Newfoundland and Labrador must undergo two levels of review: one by the provincial Health Research Ethics Board (HREB) and a second by Aboriginal communities themselves. The HREB requires researchers to adhere to both the *TCPS 2* and the *CIHR Guidelines for Health Research Involving Aboriginal People* (CIHR, 2007) and will not approve projects until community acceptance has been obtained and proved through submission of a community-researcher agreement (where a research authority exists) or a support letter through consultation (where no research authority exists).

4 Revamped and renamed Network Environments for Aboriginal Health Research (NEAHR).

5 This is not to say that every research project is required to incorporate spiritual or cultural components. For example, a study designed to

identify the prevalence of a chronic disease may not explicitly refer to the spirit world. However, Aboriginal peoples may appeal to these views, and it will become part of the research whether the researcher anticipates it or not.

6 The National Aboriginal Health Organization (NAHO) was incorporated in 2000. It is designed and controlled by Aboriginal peoples while advocating for the health and well-being of all Aboriginal peoples. NAHO has three centres – First Nations Centre, Ajunnginiq (Inuit) Centre, and Métis Centre. Each centre focuses on the distinct needs of their respective populations while promoting culturally relevant approaches to health care service and delivery. Available from http://www.naho.ca/jah/english/jah01_01/journal_p80-95.pdf

7 OCAP principles were developed by First Nations for use in First Nations communities; however, some Inuit and Métis communities also apply notions of OCAP in their governance of health research.

8 The Interagency Panel on Research Ethics (PRE) was established in 2001 by the three national funding agencies – CIHR, NSERC, and SSHRC – as a joint effort to support the development of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* available from http://pre.ethics.gc.ca/english/index.cfm   AuQ7

9 Established by CIHR's Institute of Aboriginal Peoples Health, the ACADRE Centres were implemented in 2001. These centres were developed to encourage networking and the development of Aboriginal capacity in health research. Now called the Network Environments for Aboriginal Health Research. ACADRE funding ended in 2007; funding started in November 2007 for NEAHR. http://www.cihr-irsc.gc.ca/e/4103.html   AuQ8

10 The *CIHR Guidelines* specifically state that researchers who do not comply will lose funding from that source. Because no such prescriptive measure is in place in the *TCPS 2*, there is some controversy about the policy within Aboriginal communities.

11 This community-driven approach generally elicits practical outcomes that yield direct benefits to the community (Sinclair, 2007). This is not to say that only community-based research among Aboriginal people is ethical or that all research must provide explicit benefit to a particular community.

12 Comprised of representation from Nunatsiavut Government, NunatuKavut, Shshatshui and Mushuau Innu Health Commissions, Health Canada, Labrador-Grenfell Regional Health Authority, Rural Secretariat Provincial Department, Atlantic Aboriginal Health Research Program, and the Labrador Institute-MUN Extension.

13 Especially in terms of applicability to community well-being rather than individual health.
14 F. Brunger (PI), J. Bull, J. Graham, D. Pullman, D. Wall, C. Weijer (Co-Investigators), The Labrador Inuit-Métis Research Ethics Project: An Experiment in Aboriginal Governance of Health Research in Complex Communities, CIHR Operating Grant, 2010–13 ($180,000).

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