

## RESEARCH WITH ABORIGINAL PEOPLES: AUTHENTIC RELATIONSHIPS AS A PRECURSOR TO ETHICAL RESEARCH

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**ABSTRACT:** RECENT ETHICS GUIDELINES and policies are changing the way health research is understood, governed, and practiced among Aboriginal communities in Canada. This provides a unique opportunity to examine the meanings and uses of such guidelines by Aboriginal communities themselves. This qualitative study, conducted in Labrador, Canada, with the Innu, Inuit, and Inuit-Metis, examined how communities and researchers collaborate in a co-learning environment whereby mutual interests and agendas are discussed and enacted throughout the entire research process—a process referred to an *authentic research relationship*. The purpose of this study was to answer the following questions: (1) Why are authentic research relationships important? (2) What is authenticity in research? (3) How do we achieve authenticity in research with Aboriginal peoples? This shift to more wholistic methodologies can be used in various contexts in Canada and internationally. This is the first study by an Aboriginal person to examine the perspectives of Aboriginal people, in an Aboriginal context, using Aboriginal methodologies.

**KEY WORDS:** Aboriginal health research, Aboriginal research ethics, community-based research

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**T**HE WAY ABORIGINAL HEALTH RESEARCH IS governed and practiced in Canada is changing. Recent implementation of the Canadian Institutes of Health Research Guidelines for Research Involving Aboriginal Peoples (2007), revisions to the draft second edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2009), and the emergence of Aboriginal community-based research ethics committees provide a unique opportunity to examine the meanings and uses of research ethics guidelines by Aboriginal communities themselves.

I discuss findings from a qualitative study conducted in Labrador,<sup>1</sup> Canada, with the Innu, Inuit, and Inuit-Metis<sup>2</sup>

of the region. I focus on how participants characterize the way in which communities and researchers collaborate together in a co-learning environment, whereby mutual interests and agendas are discussed and enacted throughout the entire research process. I conclude the paper with a discussion of the implications and future directions that this research suggests for guidelines for research involving Aboriginal people.

### *Aboriginal Research Ethics: Theory to Practice*

It is imperative “to view contemporary ethical standards for Aboriginal health research within a broader historical context and through both Aboriginal and western scientific perspectives” (CIHR, 2007, p. 12). Ethical research in an Aboriginal context may require altering the proposed methodology to be wholistic rather than individually centered, and it may require a shift in the researchers’ understanding of “ownership” or “sharing” of traditional knowledge (Bull, 2009).

For example, due to the historical context of unequal power relations, it is particularly important that methodologies reflect (or at least do not contradict) local Aboriginal cultural norms and community values, rather than reflecting norms and values held by the researcher or research institution (Weaver, 1997). Ownership of data and sharing of traditional knowledge (TK) is a second example of how institutional values may have to be challenged. The importance of protecting TK stems from questions of fundamental justice and the need to protect and preserve cultures (Dei, Hall, & Rosenberg, 2000). Due to an increase in mainstream interests in TK, such protections are needed to minimize misuse and misappropriation of traditional Aboriginal beliefs (Smith, 1999).

Until the late 1990s, ethical guidelines and principles such as those contained in the *Belmont Report* (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979), the *Declaration of Helsinki* (World Medical Association, 2000), and the *Tri-Council Policy Statement* (Interagency Advisory Panel on Research Ethics, 1998) have either not included, or merely paid lip service to, the unique factors involved in research with collectivities. The exception,

*The International Ethical Guidelines for Biomedical Research Involving Human Subjects* (1993), did state that some research may need to have cooperation and consent from a group's leadership before obtaining individual consent.

The initial policy developed in Canada by the Tri-Council Working Group (1996) had contained a section on research involving collectivities, but the final *Tri-Council Policy Statement* (TCPS) did not. In its place was Section 6, a temporary "placeholder" devoted to research involving Aboriginal peoples. The preface to Section 6 noted that insufficient consultation had occurred and it was premature to establish policy for ethics involving Aboriginal peoples. The preface further stated that the section should be developed through discussions and consultations with Aboriginal peoples. In 2003, the Interagency Advisory Panel on Research Ethics (PRE) committed to revising Section 6 of the TCPS.<sup>3</sup> The draft second edition of the TCPS includes a full chapter on research involving Aboriginal peoples.

Meanwhile, in the early 2000s, the National Aboriginal Health Organization (NAHO), in conjunction with the First Nations Centre (FNC), developed protocols to aid in ethical research within Aboriginal communities. These protocols were based on the principles of OCAP (Ownership, Control, Access, and Possession).<sup>4</sup> This was explicitly "a political response to tenacious colonial approaches to research and information management" (Schnarch, 2004, p. 80). Drawing on the OCAP principles, the Aboriginal Capacity and Developmental Research Environments (ACADRE) centers, in collaboration with researchers and Aboriginal communities, the CIHR Ethics Office, and the CIHR Institute of Aboriginal Peoples' Health, conducted background research to begin creating a set of guidelines for research involving Aboriginal peoples (PRE, 2005).<sup>5</sup> Out of that process, CIHR created an external advisory body, the Aboriginal Ethics Working Group (AEWG), in 2004. That group then collaborated with the ACADRE centers, Aboriginal communities, and scholars in Indigenous studies, anthropology, ethics, law, medicine, public health, and the natural and social sciences (CIHR, 2005). The result was the *CIHR Guidelines for Research Involving Aboriginal Peoples* (2007).

December 2008 marked the first round of funding competitions in which the CIHR Guidelines were in effect. In that same month, the Interagency Advisory Panel on Research Ethics (PRE) released a revised draft of the *Tri-Council Policy Statement* (TCPS), including Chapter 9—research involving Aboriginal peoples. The Aboriginal Research Ethics Initiative's Consortium (which includes representation from five national

Aboriginal organizations and the Interagency Advisory Panel on Research Ethics Technical Advisory Committee on Aboriginal Research [PRE-TACAR]) guided the discussions around Chapter 9. Meanwhile, PRE has established a Harmonization Committee with the three granting councils, the CIHR Institute of Aboriginal Peoples' Health, and the CIHR Ethics Office to work toward harmonizing the CIHR Guidelines with Chapter 9 in the TCPS. This seemed a propitious time to learn how Aboriginal communities characterize the "authentic" or collaborative process that the CIHR Guidelines sought to establish.

## Method

The research design was informed by a community-based participatory approach that fosters attention and sensitivity to the values and beliefs of community members; gives community members a sense of ownership over the project; and removes the impact of colonization, neocolonialism, and marginalization (Davis & Reid, 1999; Dickson, 2000; Haig-Brown & Dannenmann, 2000). The aim of participatory approaches is to produce knowledge that can be applied to the needs of the research participants, while also fulfilling the goals of the researchers by contributing to scholarly knowledge (Dickson, 2000).

A significant factor in a participatory approach is the realignment of roles of "researcher" and "subject," with the assumption that all parties involved bring their own set of theoretical and experiential knowledge. Consequently, many of the aspects of research that are normally considered preparatory (e.g., selection of consultants, ethics review, sampling and recruitment of subjects, informed consent) are a vital aspect of authenticity or wholistic methodology and are described here in considerable detail.

## Participants

The Labrador Aboriginal Health Research Committee (LARHC) assumed the role of community advisory team. This group is comprised of representatives from NunatuKavut (formally the Labrador Metis Nation), Nunatsiavut Government, Sheshatshiu 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-Memorial University of Newfoundland Extension. This group was actively engaged in the research process from conceptualization to dissemination and beyond

(research relationships continue to flourish on multiple projects in the area).

#### *Ethics Review*

Two academic institutions (University of Prince Edward Island and Memorial University of Newfoundland) granted ethics approval for this study, as did four community-based organizations (Nunatsiavut Department of Health and Social Development, Labrador Metis Nation Social Sector, Sheshatshiu Innu Health Commission, and Mushuau Innu Health Commission).

#### *Sampling*

One-on-one interviews were conducted with 15 participants. A purposive sampling strategy was used by the community advisory committee to recruit participants. Based on recommendations from the community advisory committee, study participants included both Aboriginal and non-Aboriginal persons. The four non-Aboriginal participants were recommended based on their job position, involvement with the community, and/or interest in ethical governance in Aboriginal communities. For the 11 Aboriginal participants, the intention of the recruitment strategy was not to have representation of “lay Aboriginal perspectives,” but to work with those members of the Inuit, Innu, and Inuit-Metis communities who self-identified or were identified by others as leaders in the “community”<sup>6</sup> and who had a personal or professional mandate to act on behalf of the community to advocate for ethical research.

#### *Informed Consent Processes*

Following recommendations contained within the *CIHR Guidelines for Research Involving Aboriginal Peoples* (2007) and guidance from the local Aboriginal communities, ongoing consultations and communication occurred between the researcher and the community advisory committee. E-mail updates and periodic conference calls provided the advisory team with project status reports, and opportunities to provide feedback and to engage in the research process in any way they chose.

The consent process began by seeking consent from relevant authorities. The differing political and social structures of the communities informed the negotiation process. In some cases, it was most appropriate to obtain consent from the Chief and Council, while in others, it was more appropriate to go through managers of specific departments, and in still other cases it was most appropriate to go through a research advisory committee

member. In Labrador (as elsewhere) there is no standard procedure for obtaining collective consent.

The study’s community advisory committee did not require a written memorandum of understanding. In its place is an unwritten agreement between myself and the communities involved that any further aspects of the study (such as publications and presentations) will be discussed with them prior to public dissemination.

The collective consent process would be more complex and stringent if community (“non-expert”) members were being asked to participate. The complexities of collective consent continue to be examined by various researchers, including Brunger and Weijer. They propose a “politics of risk” framework—that is, the ongoing process of community negotiation of collective research risk in relation to community identity—for understanding and managing collective consent (Brunger, 2006; Brunger & Weijer, 2007).

All individuals who participated in the study signed a consent form. The option of oral consent was given, as a means to enact principles of authenticity by being culturally aware. No one opted to give oral consent for this study. The need for collective consent does not erode the researcher’s responsibilities to the individual and the necessity of individual informed consent.

#### *Data Collection: Interviews*

I conducted 15 one-on-one interviews. The interview consisted of 12 questions and probes (Appendix A). Interviews ranged from 30 to 90 minutes, with an average of about 60 minutes. Participants were asked if they required translation services prior to participating, but no one required this service.<sup>7</sup> Fourteen interviews were audio recorded and transcribed verbatim. One participant chose not to be audio recorded. In that case, the field notes were expanded to text and sent to that participant to ensure accuracy. The other 14 participants were also given the opportunity to review their transcript prior to analysis. Three participants chose to do so.

#### *Analysis*

The analysis process is iterative and progressive. This process resulted in several reviews of the interview transcripts, field notes, literature reviews, and community consultations. Throughout the analysis stage, key informants and community advisory members were available for follow-up and clarification. After the analysis was complete and the final report written, the community advisory committee was given the opportunity to review the document and provide feedback. Community

members from the advisory team also shared their expertise in local history and processes.

The research findings are presented as a “collective voice” of the Innu, Inuit, and Inuit-Metis of Labrador. The collective voice is the voice of the Labrador Aboriginal community, of which I am a part. This method of writing and representation serves to maintain the confidentiality of individual participants. Quotes are not identified with specific speakers or the groups that they “represent.” The consensus was that no one person can truly represent *the* unique perspective of “the Innu,” “the Inuit,” “the Inuit-Metis,” or “the Aboriginal Peoples” of Labrador.

This is a novel approach that I am developing as a specifically Aboriginal way of representing the voices of the community. Because I am part of this voice, it is appropriate to use this method; however, this is not to say that a researcher from outside the community could, or even should, do this. The community advisory committee reviewed the results and applauded the outcome.

## Results and Discussion

The following sections provide insight regarding three questions: (1) Why are authentic research relationships important? (2) What is authenticity in research? (3) How do we achieve authenticity in research with Aboriginal peoples?

### *Why Are Authentic Research Relationships Important?*

Authentic research relationships are collaborative relationships that enable the researcher to learn enough about the Aboriginal culture that is to be studied to understand the concerns that these populations bring to the experience of being researched, and to be able to respond respectfully and appropriately to the peoples studied and their community. The main issues that concerned the peoples I interviewed were (a) false generalizations and simple notions about assimilating these diverse cultures; and (b) the lack of meaningful benefit of research to the communities studied.

### ASSIMILATION, EXPLOITATION, AND EXOTICISM

Respondents linked issues in research to the history of colonization of Aboriginal peoples, and in particular to the explicit attempts at cultural assimilation.<sup>8</sup> They expressed concern about a common misconception that “all Aboriginal people are the same” and that governments or researchers are going to “assimilate [us] all into one box.”

One often-cited example of how researchers continue to base their assumptions on an assimilationist perspective

is the overuse or misuse of terminology to describe Aboriginal communities. For example, some respondents commented that “The word ‘Aboriginal’ should never be used . . . because it tells you nothing: who’s Aboriginal? [Inuit] like to be called Inuit, Inuit-Metis like to be called Inuit-Metis, First Nations like to be called First Nations.” These respondents prefer their individual cultural designations to be used.

Though participants noted that threats of physical harm or financial exploitation were problematic, concerns are shifting to “a more subtle way of misrepresenting people.” If the research is with Innu, for example, and the researcher unknowingly includes an Inuit community, the results may be inaccurate. Exploitation also continues in research where Aboriginal peoples are exoticized: “Quite often, when you get involved in research, you’re influenced by numbers and statistics and exotic backgrounds of people and things like that.” Research continues to be conducted based on the *exotic* nature instead of the actual *needs* of the community. For example, “the Inuit are in the limelight [because] it’s Circumpolar [Year, 2008] and International Polar Year and the whole issue of Canadian sovereignty in the Arctic.” This kind of public attention places emphasis on a certain group of people, making them more “attractive” to researchers.

In the quest for knowledge or to (dis)prove theories, researchers have “quoted out of context,” and “didn’t give back to the community,” which has added to the feelings of distrust toward the researcher by the community. The good-natured way of living for Aboriginal peoples is taken advantage of when researchers “take what they want and then leave.” People gladly share their stories and provide hospitality to the researchers.

### BENEFITS OF RESEARCH AND CHALLENGES OF FUNDING

Multiple research projects have been conducted with Labrador Innu, Inuit, and Inuit-Metis. With no immediate benefit to individuals or to the community, the general response is that “people are sick of being studied to death.” With no clear direction and multiple investigators asking the same questions, community members feel over-researched “because it’s the same questions over and over and over again, and they don’t see anything for it.” The gain or benefit to the community does not have to be a direct one from the actual research: “Maybe they should do volunteer work in the community while they’re there, or involve students and train them.”

The sense of being “researched to death” is exacerbated when the research fails to have relevance or applicability to the participants. When some benefit stems from the research (direct, indirect, individual, group, or capacity

building), however, communities do not feel exploited or alienated. Community members generally recognize the importance of research and want to actively participate in researching their communities “back to life.”

A practical implication that is often overlooked is the money involved in conducting such research. Funding agencies generally do not provide adequate funds at the beginning of a project to establish and build necessary relationships. Moreover, some Elders have come to expect a certain level of financial compensation for the time and knowledge they share, but those costs may not be built into the research budget. This may especially be problematic for graduate students or new faculty members who generally have less funding to engage in research.

Thus, we see that authentic processes in research are ones that enable researchers to understand the cultures and values of the people they study, and enable the peoples studied to participate actively in the process. This co-learning process is important because it enables the researchers to produce valid knowledge that will be useful to the peoples studied.

#### *What Is Authenticity in Research?*

Authenticity in research means employing processes that allow the researcher to learn and be responsive to an Aboriginal mindset, which tends to be very different from a Western mindset. This enables researchers to understand and care about aspects of the specific Aboriginal interpersonal style and concepts about self and others, rather than operating on Western assumptions about people. It is now possible to engage Aboriginal peoples in ways such that their culture can be experienced and understood. With changing political structures and policies regarding the ethical governance of research—nationally, provincially, and locally—Aboriginal peoples in Labrador are actively involved in ethical guideline development and are engaged in meaningful partnerships with funders and researchers. “The political climate of Labrador now is that . . . this pendulum is swinging where . . . once people were very not interested or not aware of [research] and now they’re very, very focused on it.” It also involves mutual respect. “And with this comes knowing how to treat each other appropriately and caring for what people have to say and the past experiences they have had.” It is not sufficient to contextualize a research project in contemporary time alone: for Aboriginal peoples, there is an important connection to the past and the future which must be taken into consideration. An Inuit-Metis Elder describes this connection:

I am one man. One Metis man who is connected to the universe in many ways. I am connected to my past by my relations with the grandmothers and grandfathers. I’m connected to the future through my children and grandchildren. I do not stand alone in this world. I am merely one small element that is tied to the water, land, sky, and wildlife. I am part of the environment and the environment is part of me. We cannot separate ourselves from that and assume that we can make it in this life. Our people who separate themselves from their environment and their past and future generations are hurting and they seek direction in finding their way back home. We must know where we come from in order to know where we are going. All of us, strong Metis people, must never lose sight of our connections.

#### *How Do We Achieve Authenticity in Research with Aboriginal Peoples?*

The preceding sections highlight why authentic research relationships are necessary and provide some insight into what this authenticity may look like. The remaining discussion concerns *how* to achieve such authenticity. Authentic research involving Aboriginal peoples requires attention to ethical conduct throughout the research process. “[E]thics is not a stage of research completed at the start of a project by filling out a generic form and receiving approval from an institution.” Rather, from Aboriginal perspectives, ethics involves “consultation, consent, and dissemination,” which includes ongoing investment in the community. “Ethical research . . . is research conducted with the full knowledge, the full consent, the full cooperation of the intended study participants.”

#### COMMUNITY CONSENT

The consent process for any research involving humans is complex and requires more than obtaining a signature. Study participants emphasized how this is particularly important for research involving Aboriginal peoples. As one participant stated, “Permission is the first line of ethical behavior, and that’s not as easy as it might sound.” Getting this permission requires establishing a relationship with the community from the onset and delivering an end product. Essentially, consent is regarded as a two-way process in which both parties—researchers and the community—agree to certain elements of a reciprocal relationship.

It was noted that just because “people have to go through ethical reviews at the university . . . does not

mean that the research is ethically appropriate for communities in Labrador.” This collision of two worldviews requires that researchers and communities actively engage in the research to ensure that local community understandings of the consent process are respected and adhered to.

#### CONSENT IN RELATION TO POWER

There are concerns in Labrador that research may be approved by communities, in the absence of a thorough review, out of a kind of blind trust in the researcher. Specifically, the concern is that “people are not being well informed of what the research entails and are only getting one side of the story.” There is a fear that researchers use technical jargon and overly emphasize the potential study benefits. “[I]t would be easy for somebody that had a good reputation and profile to allege that they conducted research . . . [and it may then] be accepted by the greater public just because of who [the researchers] are, without it really being reviewed.”

#### CONSENT AS PARTNERSHIP

In the past, research has been conducted with little or no community involvement. “[R]esearchers have [this idea] that . . . academic freedom means that you don’t have that obligation to people; it takes a long time, if you’re academically trained, to . . . see that the community has a stake in what you’re doing.” It is important to “always understand the culture you are working in and respect cultural norms and local customs.”

When relationships are established between researchers and communities, there is an opportunity to negotiate and discuss the research process. Expectations can be clearly defined and responsibilities tasked appropriately. “This dialectic relationship facilitates mutual learning and minimizes the risk of misrepresentation. It’s not anymore the expert coming in . . . and parachuting in to do a research project. It’s meshing expertise with community needs.” These relationships have to be developed through an understanding of local customs. “They just can’t come in and give us air time, but not actually demonstrate that they understand what our culture is and what’s important.”

#### CONSENT AS DISSEMINATION

Researchers are required to “share the results with the communities” and to provide an opportunity to be “engaged in the interpretation” of results. Giving back to the community is essential. “[W]hen researchers come in and collect information, then they have an obligation to come back to the community to tell them what the results are.” This can be done in a variety of ways, such

as reports, papers, brochures, posters, or presentations. Generally, when researchers commit to providing an end product to the community, they follow through; however, a recent example in Labrador illustrates the situation where the researcher did adhere to guidelines and worked closely with the community but then vanished with the research results.

A university came in and promised that they would, in fact, come back to the community and would give information . . . and it had to do with heavy metals and . . . contamination. [A]t this end [we] helped out: went out to the communities, did the interviews, collected the data . . . and then sent it back to the university. [We didn’t hear back from the] principal [investigator] and [the community liaison] didn’t know what happened to the research and whatnot. And then I read in the *National Geographic* . . . *Canadian National Geographic*, some of the results of the research of the research project.

#### ABSENCE OF CONSENT

There are two recent examples of medical professionals practicing in Labrador who conducted research with no consent from research “subjects.”<sup>9</sup> In one instance data were collected without people’s knowledge, and in the second instance a researcher accessed local suicide statistics without permission. The researchers shared their findings with others, but not directly with the community.

#### COMMUNITY CONDITIONS

One of the highest priorities for Aboriginal communities in Labrador is to initiate their own research. This is seen to be the surest way to have ownership, access, and control over research to ensure that research will yield results with local relevance.

#### OWNERSHIP, CONTROL, ACCESS, AND POSSESSION (OCAP)<sup>10</sup>

It has only been “in the last few years that people [in Labrador] are recognizing how much of a benefit that might be to communities . . . to be involved . . . and to decide on what kind of research is happening in their community.” It is “only with that—the advent of people wanting to see health research—that then the ethical guidelines become an important issue.” Part of that issue “for the communities here in Labrador, of course, is the whole OCAP issue.”

Though a lot of research is currently not initiated within the region, outside research is being denied if it does not fit local priorities and ethics protocols. “So it’s

done the complete shift from the helicopter research to much more participatory; and I don't think we're where we need to be, which is where we would identify the issue." Now that "communities are much more actively involved in understanding their rights to research," there is notable improvement in the way in which research is conducted: "[T]he difference is now that we're an active participant."

#### RESEARCH RELEVANCE

The consultation process between communities and researchers will allow communities to voice their concerns with research and research priorities. "So we need to make sure that the research that's taking place is on topics that are going to be beneficial to us and not only to the researcher to get their masters degree." It was noted that "the most important thing is that research is not done [just] for the sake of research." To foster this research relevance, "there is an onus on the community to articulate what it is we want information on." Research should entail more "relevance to the community" and not focus entirely on scholarly curiosity. As an extension of self-governance, and in response to a history of exploitation in research, research relevance to the community is paramount. "[F]or all of the information that was gleaned from people that live here, we haven't seen the benefit of it in the past—very unethical." The lack of benefit is an issue because of the long-standing history of *giving* information and not *receiving* anything in return.

#### Conclusion

Authenticity is not necessarily synonymous with ethical research, as it also incorporates political and epistemological caveats. In research with Aboriginal peoples, the precursor to ethical research is an authentic relationship—that is, how communities and researchers collaborate together in a co-learning environment whereby mutual interests and agendas are discussed and enacted in the entire research process. The history of Aboriginal peoples with oppression, particularly by researchers, has shaped the concept of authenticity and the context in which trust becomes paramount.

Some of the concerns expressed by Aboriginal participants are rooted in non-Euro-American values and ethical systems; however, many Aboriginal values, ethics, and epistemologies are parallel to aspects of Western views. The problem that arises is a disconnection between the ideologies and theories of *how* to conduct ethical research, and the practice of conducting ethical research.

Another disconnect that gives rise to dissatisfaction with research is between what the researcher understands about the value of basic research and what Aboriginal peoples expect from research. Research does not necessarily lead to an important and practically useful discovery. However, Aboriginal peoples are unclear about what research can and cannot do, and about the ease with which any researcher, Aboriginal or otherwise, can obtain funding. The assumption that all research can or should translate into action for the community, and that this could be made to happen if Aboriginal peoples took the lead in research programs, was evidenced in a discussion with one community member who had expressed the need to have an internal research coordinator who could procure funds to conduct research. This community member held an idealistic and naive conception about the ease with which research funding can be secured. "[T]hey'd have to solicit proposals and sort of pay for herself, which we're very confident can be done." A greater understanding by Aboriginal peoples of the research process and of the inherent uncertainty concerning potential outcomes is needed. An important aspect of creating research capacity in Aboriginal peoples is instruction in the scientific method. This will inevitably instill a greater level of trust and understanding between communities and researchers.

#### Best Practices

Researchers are advised to be transparent as to their intentions, to invite members of the community to be engaged in all phases of the research as co-researchers, to contribute to the research capacity of community members, and to be faithful to the memorandum of understanding that they have crafted with the Aboriginal community about ownership of the research data (Weijer, 1999; Weijer et al., 1999; Bull, 2010).

#### Research Agenda

Further research and analysis of how Aboriginal peoples conceptualize and experience authentic relationships with researchers is a critical next step.

#### Educational Implications

Training in ethics of research involving Aboriginal peoples is needed in various settings, with various stakeholders: community members, academic-based researchers, research ethics review board members, and policy makers. Community members are required to know their roles and responsibilities in research and

understand the parameters of academic research. Academic-based researchers need to understand their roles and responsibilities to Aboriginal communities and recognize the significant role that history plays in Aboriginal persons' perception of research. Research ethics review board members need to revise their procedures to require community review of research and written approval prior to REB submission and approval. As a means to advance these educational implications, policy makers should learn to appropriately promote and advance the guidelines for research involving Aboriginal peoples. Moreover, capacity building between and among all people involved is required to ensure that ethical best practices are being implemented and meaningful dialogue can occur during times of contention.

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### Author's Biographical Sketch

**Julie Bull** is now working on her Ph.D. in Interdisciplinary Studies at the University of New Brunswick. Her research is rooted in Aboriginal and rural health and education. Julie has received numerous awards and recognition in acknowledgment of her scholarly abilities, and her promise as an Aboriginal researcher who conducts research with Aboriginal populations.

### End Notes

<sup>1</sup>Labrador is situated on the Canadian mainland, northwest of the island of Newfoundland on Canada's east coast, and has a population of approximately 27,000 people (Statistics Canada, 2006). Labrador is home to Innu, Inuit, Metis (Inuit-Metis), and non-Aboriginals.

There are two Innu, five Inuit, and 14 Inuit-Metis communities. Most of western and central Labrador and some areas in the south are inhabited predominately by non-Aboriginal people.

<sup>2</sup>The Inuit-Metis in Labrador do not use the accent over the 'e' (Metis).

<sup>3</sup>The Interagency Advisory Panel on Research Ethics (PRE) was established in 2001 by the three national funding agencies—CIHR, SSHRC, and NSERC—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>.

<sup>4</sup>The National Aboriginal Health Organization was incorporated in 2000. It is designed and controlled by Aboriginal peoples, while advocating the health and well-being of all Aboriginal peoples. NAHO has three centers—First Nations Centre, Ajunnginiq (Inuit) Centre, and Metis Centre. Each center focuses on the distinct needs of their respective populations, while promoting culturally relevant approaches to healthcare service and delivery. Available from <http://www.naho.ca/english/>.

<sup>5</sup>Established by CIHR—Institute of Aboriginal Peoples' Health, the ACADRE centers were implemented in 2001 across Canada, with the intent to encourage networking and the development of Aboriginal capacity in health research. Now called Network Environment for Aboriginal Health Research (NEAHR). ACADRE funding ended in 2007; funding started in November 2007 for NEAHR. <http://www.cihir-irsc.gc.ca/e/4103.html>.

<sup>6</sup>Meaning the overarching "community" of Aboriginal peoples in Labrador, not specific geographic or cultural differences. The purpose of this study is not to distinguish cultural norms or to identify subtle or unsubtle nuances that further complicate the ethics review and engagement process.

<sup>7</sup>Final one-page summaries of the research study were translated in the traditional languages of the Innu and Inuit (Innu-aimun and Inuktitut, respectively).

<sup>8</sup>The political history of assimilation, exploitation, and exoticism are interrelated as a cluster of concepts; therefore, they are addressed together in this section. A series of concerns may appear to relate to a specific point (e.g., not giving back to the community) but are really fundamentally about this cluster of three concepts.

<sup>9</sup>Use of the term "subjects" purposefully illustrates that this was not a collaborative approach, but rather that participants were being researched "on."

<sup>10</sup>Interestingly, most participants referred only to ownership, control, and access because they recognize a lack of infrastructure in place to adequately store data and research.

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### Appendix A: Interview Guide

1. To your knowledge, how often is health research done in your community?
2. Who are the people doing the research? What university or other organization do these people come from?
3. What guidelines or procedures does your community have in place to review or monitor research? Are there other things being planned? Wish list?
4. What resources does your community use to review or monitor research? What resources does your community need?
5. Do you know what other Labrador communities are doing with regard to research review and monitoring? Other Canadian Aboriginal communities?
6. Have you had a chance to review the CIHR AE guidelines? Thoughts? Active involvement in process/consultation as guidelines were developed?
7. Do you think that these National guidelines reflect the way in which you think research should be conducted? Do you think there are differences in these National standards and your local standards?
8. What does unethical research mean to you?

Do you have any examples/stories about unethical research done in your community?

The unethical use of research results?

9. What does ethical research mean to you?

Do you have any examples/stories about ethical research done in your community?

Do you have any examples of good collaboration in research between researchers and your community (what you would consider a success story)?

10. Have you heard of the Newfoundland and Labrador Health Research Ethics Authority? (If not, provide contact number for information.)

If yes, what are your thoughts on it? Do you think it is helpful? Useful? How do you see your community procedures fitting in with a provincial authority?

11. Are there any phrases, or words, or traditional stories in your language that might help to explain any of what you have discussed?
12. Do you have anything further you would like to add? Any questions, comments, or concerns?