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Ethics in Aboriginal Research: Comments on Paradigms, Process and Two Worlds

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ACKNOWLEDGEMENTS

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ABSTRACT

There is emerging agreement that research with Aboriginal peoples [4]and communities must involve both the researcher and community in a reflexive process of negotiation, and must build research/community capacity for research. This shift reflects a move from deductive, empirical university and academia-driven models to a more holistic, community action-oriented approach that is Aboriginal-driven. The research is often participatory, inductive and qualitative in nature, calling for flexible research ethics board (REB) procedures. This paper examines these new protocols, and documents some recent researcher experience with communities, research funding bodies and university/hospital/government REBs.

BACKGROUND

This article was produced from the experiences of the authors, and by a review of Aboriginal ethics and research literature. Of some 100 protocols and articles produced over the last 20 years in Canada and

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[4] The term 'Aboriginal' includes Inuit, Métis and First Nation (both Status and non-Status) peoples. It reflects an incredible diversity of languages, culture, values and worldview. Our use of the term also includes the concept of 'Indigenous' as being "the tribal peoples […] whose distinctive identity, values and history distinguishes them from other sections of the national community [who] despite their legal status, retain some or all of their social, economic, cultural and political institutions" (Ermone et al., 2004, p. 5).

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the U. S., there are many common themes echoed today in leading topics of discussion and debate involving research, ethics, and Aboriginal communities. This article primarily reflects the authors' personal reflections on researcher experiences moving between community and academic worlds, and presents practical applications of the principles found in the 'new' Aboriginal research ethics.

> There is a persistent form of divergence, an alienating tension, at times bordering on animosity, that tarnishes and hangs like a dark cloud over the precarious relationship between Indigenous Peoples and the Western world […] The schism continually reminds us of the anguished legacy of the Indigenous/West confluence that festers in a convoluted entanglement between the two worlds leading to the failure of arriving at a mutual and amiable meeting of minds […] The cultural tensions looming over the Indigenous/West relations, in their historical dimension, are particularly magnified on the contested ground of knowledge production and in particular its flagship enterprise of research. (Ermine, 1995, p. 1).

In a 2002 brief, *Governance of Research Involving Human Subjects*, Canada's National Aboriginal Health Organization (NAHO) points out that: "Research has often had ambiguous qualities for Aboriginal people. Some Aboriginal individuals and communities have been 'subjects' of research that has resulted in variable outcomes; some positive, some negative and some with both outcomes" (National Aboriginal Health Organization [NAHO], p. 3). More bluntly, as voiced by the Assembly of First Nations (AFN) (2001), "Aboriginal communities have been 'researched to death' with few positive outcomes or improvements in their communities" (p. 8).

> Today, in keeping with current movements toward self-determination in Canada, Aboriginal and non-Aboriginal groups are now looking at new ways of defining Aboriginal research protocols. Aboriginal interests are currently geared towards surviving and thriving through self-determination and control over resources including cultural and knowledge resources [...] the result of the decolonization agenda that has as a principle goal, the amelioration of disease and the recovery of health and wellness for Indigenous populations (Ermine et al., 2004, p. 6).

This is reflected in a 2002 brief from the Saskatchewan Indian Federated College (now First Nations University) recognizing the need for a "paradigm shift" in Aboriginal research ethics. This brief opens with the observation that the Royal Commission on Aboriginal Peoples and the Tri-Council (Social Sciences and Humanities Research Council, National Science and Engineering Research Council, and Canadian Institutes for Health Research)

> Agree that a significant element of the solution [to the costs of social problems facing Indigenous peoples] is the need to shift the research paradigm from one in which outsiders seek solutions to 'the Indian problem' to one in which Indigenous people conduct research and facilitate solutions themselves.[5]

An example is the Canadian Aboriginal AIDS Network (CAAN), a national HIV/AIDS Aboriginal organization that represents over 200 organizations (including some 150 Aboriginal AIDS Service Organizations (AASOS) across the country, at local and regional levels) and individuals. CAAN has been involved in community-based research (CBR) for at least 10 years and this involvement has, since the beginning, been guided by the right of self-determination and control over the research process. Today, CAAN is involved in a number of research projects ranging from issues of mental health (i.e., the experience of depression), to HIV testing for Aboriginal

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[5] "The revision of Section 6, 'Research involving Aboriginal Peoples', of the Tri-Council Policy Statement: Ethical Conduct for research Involving Humans (TCPS) was undertaken by the Interagency Advisory Panel on Research Ethics (PRE) in 2003. It is based on principles of open, inclusive and participatory public processes, engaging Aboriginal peoples and the research community, drawing on diverse disciplines and cultural approaches, fostering constructive collaborations and partnerships while building on international, national and local models (e.g. especially those respectful of Aboriginal knowledge, methodologies and communities" (personal communication, Thérèse De Groote, PRE, June 2006). Membership in the consortium includes five national Aboriginal organizations as well as the three granting agencies, and PRE. This TCPS initiative will build on parallel initiatives such as the CIHR 'Guidelines for Health Research Involving Aboriginal Peoples" written by its Aboriginal Ethics Working Group comprised of Indigenous scholars who are also community people.

youth, to the experience of stigma and the importance of cultural competence in service provision. The goals of these research efforts include providing information and resources to communities to effectively respond to the HIV epidemic in Aboriginal communities. In the context of this research involvement, issues of ethics have been at the forefront, including how best to balance cultural needs and perspectives against the requirements of research ethics boards (REBs). CAAN's involvement in research seeks to contribute to Aboriginal community efforts in preparing an effective response to HIV/AIDS in Aboriginal communities, including influencing evidence-based approaches to both programs and policy.

Working with Aboriginal peoples and communities should involve the researcher and community in a reflexive process of negotiation, and build community capacity for research. This shift reflects a move from deductive, empirical university and academia-driven models to a more holistic, community action-oriented approach to research that is Aboriginal-driven and takes into account the uniqueness of each community.[6] The central notion here is the diversity of Aboriginal communities, and of types of communities (such as those served by AASOs in cities and on reserves).

> There has been some ambivalence around the need for national ethics guidelines. There has been some sense that the solution may lie in creating effective research protocols at the local level, because such protocols reflect and respect individual differences in protocol among various Aboriginal peoples (e.g., the Blackfoot emphasize approval by responsible individuals, not community political representatives; in other Aboriginal communities approvals are given by families that are responsible for various kinds of knowledge) (McNaughton & Rock, 2003, p. 11).

Although some have proposed enforceable, national ethics guidelines in Aboriginal research, this may be impossible, given the need for local, community-based ethics requirements.

BRIDGING TWO WORLDS

The new Aboriginal research paradigm calls for an agreement on research protocols between researchers and the community. Specifically, it calls for a research agreement with the community. In practice, researchers are finding this to be *more process than product*. Where Research Ethics Boards (REBs) call for a 'written in stone' plan of action, work in the community involves a constant learning/and changing process that is oral in nature, flexible and open-ended.

The idea of two worlds and worldviews also comes into play in this process, and researchers become experts in knowledge translation and exchange:

> REBs need direction in order to appropriately assess research protocols dealing with Aboriginal communities without sacrificing the scholarly value of the research. For REBs that rarely view protocols for community based participatory research, the assistance of not only community representatives and Aboriginal researchers, but also outside experts (familiar with both worlds) is necessary. (Kaufert, Glass, and Freeman, 2005, p. 82)

As researchers we often find ourselves moving between the communities on many levels, from meetings with council to attending ceremonies and other gatherings, to the concrete world of REBs and biomedical research ethics.

> Mike Patterson: *When doing my MA thesis, I was required by the REB to get written consent from my 'research subjects' (we still used that term then) to quote them. I was dealing largely with Elders, and we met on many levels over the course of many years. They became mentors, advisors, and friends. As I was wrapping up my thesis, I presented the consent forms to a couple of Elders,*

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[6] Aboriginal-driven often means and includes research that takes into account cultural beliefs, values and practices (e.g., Elder involvement, etc.).

who refused to sign. I realized that our relationship was beyond that of researcher/subject, and that the forms were an intrusion. When the university asked for the forms, I explained the situation, provided a list of names, and said they were free to contact these Elders about the nature of our relationship and study. We never heard back from them.

The central question is how best to bridge the world of academia with the more fluid Aboriginal community reality. Accounting for differing perspectives and worldviews often requires flexibility on each side. CAAN has developed a process of negotiation that recognizes the need for a researcher's need for a 'written in stone' plan of action while simultaneously allowing for ongoing dialogue and open communication:

Randy Jackson: *CAAN makes it a regular practice to negotiate the research process in writing at the outset, though the written contract itself is entirely amenable to change at any point (i.e., Principles of Research Collaboration. See Appendix A). When first used, and as the research project (i.e., HIV Testing and Care Decisions for Canadian Aboriginal Youth) entered the writing phase, the issue of authorship became more paramount and dominated discussions among research team and advisory committee members. It became apparent that the original written contract would require changes that addressed these concerns. An addendum was negotiated, signed by all parties, and laid the foundation against which authorship could respectfully be addressed. This process was so successful that it continues to be used across all of CAAN's research projects, particularly where research involves university, hospital/or government-based academics who typically are expected to publish in peer review journals.*

COMMUNITY CONSIDERATIONS

From an Aboriginal perspective, research ethics and protocols have more to do with doing good for the community, beyond the protection of individual 'subjects,' so researchers must go beyond the standard scientific or medical ethical model to work with Aboriginal communities. Protocols developed by the REBs do not take community involvement into account; for instance they do not call for community input into ethics submissions, and do not include reference to Aboriginal ethical guidelines in their forms.

Mike Patterson: *In working on a falls prevention project in a Mohawk community, I fell into a language divide. The university REB wanted to see documents (such as consent forms) translated into the research partners' language. I thought this to be a good idea and wanted also to start translating our guide "First Nations Falls Prevention" (Lockett et. al. 2004) to Mohawk, and so had written this into our funding proposal to the Institute for Aboriginal Peoples Health at CIHR. This was also mentioned in our REB application. Once we started working in the community however, I got an unexpected reaction. The Elders I worked with strongly objected to written translation of their oral language and history. The Elders said they did not read Mohawk and that the same held true for most Elders they knew. At the same time, the REB had approved our ethics package, but was awaiting delivery of the translated consent forms. I was in a difficult position. The research team discussed this and in the end I presented our dilemma to the Elders, who graciously agreed that it would be easiest to have the consent forms translated to satisfy the REB. At our first Focus Group, the Mohawk consent forms were greeted with some confusion (nobody could read them) and a fair bit of laughter. Everyone signed the English forms, but kept the Mohawk forms as a souvenir.*

Based on a review of prominent Aboriginal ethical models (some 20 models), and highlighting those by the AFN, NAHO, CAAN, and local Aboriginal communities, we have identified seven key ethical issues which should be considered when conducting research with Aboriginal communities.

GUIDELINES FOR RESEARCHERS/COMMUNITIES

1) Although a research project may simultaneously account for academic interest (e.g. the development of theory, etc.), research must ultimately be of benefit to the community (e.g., demonstrated potential to influence policy, practice and personal/community change, etc.). Research projects should be assessed to see if they address community-relevant priority issues. In other words, the research process supports and applies the principle of Aboriginal self-determination.

2) Both individual research subjects and the community should be equally involved in all aspects of research. This promotes a holistic view of research where the contributions of Aboriginal community members and academic researchers are of equal value.

3) The principles of Ownership, Control, Access and Possession (OCAP) must be negotiated in good faith[7]. Also, OCAP is a 'living' agreement that must be revisited over the life of the project.

4) Although all the usual ethical guidelines apply (i.e., confidentiality, risk/benefit, informed consent, etc.), respect for the community and its culture is essential. Ethical consideration need also include the ethic of equal participation and consultation that incorporates local and traditional knowledge.[8] The nature of the participation by researchers and community members may differ substantially when academic and traditional knowledge come together.

5) The reciprocal process of capacity-building is undertaken where academics learn about local and traditional knowledge and Aboriginal needs for capacity-building in community based research are also met.

6) The scientific goals of the Project must be respected in this process, along with respect for and inclusion of Aboriginal knowledge (worldview) and methodologies.

7) The community should be consulted when research questions and protocols are being developed, when data is collected and analyzed, and when findings are generated. They should also be given ample opportunity for feedback and participation in the dissemination of research findings. Community input is also critical in developing knowledge translation strategies that are meaningful and appropriate to the audience, whether academic or community, for successful uptake of research results.

If research is first proposed by academics, the research process should be made clear to the community, so that the project can be assessed to see if it addresses priority issues. Many people need to be involved in this process. As described by Brant Castellano, at a Tri-Council Colloquium on Ethics held at the University of Ottawa in 2003, the researcher can be seen to be negotiating a series of gates, each of which relates to various individuals, organizations or sensitivities (such as cultural) of the community. Each of these gates may have different keepers, including Elders, people who are part of the research itself, the Band Council, or various segments of the community, such as women, veterans, and youth etc.

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[7] "Originally coined as OCA – a more resonant acronym with its nod to the 1990 Oka Crisis – OCAP is changing the way research is done" (Snarch, 2004, pps. 80-81). "CAAN understands OCAP to mean the following: *Ownership* refers to a relationship Aboriginal communities have to collectively posses their cultural knowledge, data and information. Involvement in research does not transfer ownership to any particular individual and does not end following publication. Rather, ownership remains with the collective community through its representatives. *Control* refers to an absolute right to be equally involved in all stages of research, from problem definition through to research finding presentation or publication. *Access* to the resulting data of research is a key feature of OCAP. This applies regardless of where or how resulting data is held. *Possession* refers to the mechanism that respects the concept of ownership. Typically this refers to written agreements that asserts traditional proprietary rights and incorporates cultural values and perspectives" (Barlow, Kevin et. al. 2005).

[8] "…Indigenous knowledge benchmarks the limitations of Eurocentric theory -- its methodology, evidence, and conclusions -reconceptualizes the resilience and self-reliance of Indigenous peoples, and underscores the importance of their own philosophies, heritages, and educational processes" (Battiste, 1995, p. 2), "…[It]…is not a uniform concept across all Indigenous peoples; it is a diverse knowledge that is spread throughout different peoples in many layers… Indigenous knowledge is so much a part of the clan, band, or community, or even individual, that it cannot be separated from the bearer to be codified into a [Eurocentric] definition." Indigenous peoples' worldviews are cognitive maps of particular ecosystems… Strands of connectiveness do exist, however, among Indigenous thought… [many teachings from North and South America] …reflect a cultural interpretation based on observation of the processes inherent in nature" (Battiste and Youngblood, 2000, pps. 36-37, 40).

Randy Jackson: *For CAAN research projects, negotiation of access to a research site is typically the responsibility of community members of a research team. Negotiation and preparation of ethical submissions is primarily the responsibility of academics on the team, with input by community. One process used by CAAN in a past research project (e.g., Mental Health) has been having the research design submitted first to a community advisory committee in a language and manner that is appropriate. Only after their comments and feedback are incorporated is a submission to an REB done. As a general guideline, the research process needs to be flexible to accommodate this input and project timelines must allow for this process to occur in a meaningful way.*

The research should be a partnership, or rather, many of them. CAAN, in its Aboriginal Capacity Building Program on Community Based Research (launched with Health Canada and now under CIHR), requires that research subjects and communities "be actively included in all aspects" of research, with Aboriginal participation demonstrated in all stages of the research process, including but not limited to: needs assessments (defining priority individual and community needs); identification of research questions (how best to answer these needs); collecting and analyzing data; and reporting and applying the results. Research processes need also include capacity building, for academics and communities alike.

MAKING IT WORK

Working with OCAP guidelines is a challenge for institutions in particular: The concept of ownership challenges the academic notion of intellectual property; the concept of control challenges the academic notion of academic freedom; and principles guiding community access to research data may be unfamiliar to REBs. With respect to access, REBs are particularly concerned about protecting the confidentiality of research participants and thus, community access to data may be seen as a risky proposition that fails to safeguard confidentiality. However, the OCAP guidelines bring another dimension of access into focus, one that is grounded in the concept of self-determination. That is, the importance of the community having control over not just the data, but also how it is used, and what actions are taken and by whom, in response to the findings. The sensitivity of the research topic may affect discussions regarding data ownership. The community can be questioned about its ability and resource infrastructure to safeguard data, particularly data that has not been cleaned of identifying information.

Randy Jackson: *In negotiating an ethics submission, CAAN encountered a situation where the REB continually made requests for clarification of procedures for the safeguarding of confidential information. Despite our attempts to solve this problem in writing, it took a meeting with a representative of this REB to clarify the importance of retaining community access/ownership of data collected. In the meeting, CAAN representatives spoke to issues that considered the importance of OCAP – this particular REB seems fairly forthcoming and we managed to negotiate a reasonable solution that satisfied all involved. This speaks to the importance of personal meetings in negotiations with REBs, to facilitate their understanding of Aboriginal research ethics. In the end the REB issued an ethics certificate.*

Since each community and research project is different, priorities for the applications of OCAP research guidelines will vary, depending on factors such as the nature of the research, constraints imposed by research funding bodies, or community wishes. In some cases, communities will insist on complete ownership of the research process and results, including rights to publication. Other arrangements may ensure that the community, the researcher, and the academic community will each benefit from the results.

Randy Jackson: *With respect to publication of findings, CAAN's position is one that can be thought of as joint ownership. The community is always provided reasonable and adequate time to review and respond to draft publications and presentations. In cases of disagreements over interpretation of results, a significant degree of research team consensus is always sought. Where agreements*

can't be reached, rather than bar a publication or presentation, dissenting opinions may be included in the dissemination of results. This has not happened in any of CAAN's research projects to date.

DRIVING ABORIGINAL COMMUNITY ACTION RESEARCH

The process should also help build capacity for what we propose could be called Aboriginal Community Action Research (ACAR), research initiated and directed by communities themselves. Participatory Action Research (PAR) has historically sought to involve research subjects as participants in a process toward action and positive change, Community-Based Research (CBR) goes a step further by calling for a full equitable partnership between the researchers and the community, building community research capacity and sustainable processes for further research and action. But the Action is missing from CBR; Aboriginal Community Action Research, ACAR, is what is needed to drive community involvement and capacity.

> Mike Patterson: *When we proposed a project in one community, we first went through a five hour meeting with health professionals there. They were very hesitant to endorse another research project, until I pointed out that this was an "action project," not just research; we wanted to raise awareness about the issues to effect positive change, with help and guidance of the Elders, and also build community capacity for further research. This was when they agreed to work with us.*

RIGOROUS, RESPONSIBLE RESEARCH

The call is for culturally appropriate and rigorous, replicable research, analysis, and dissemination strategies that are beneficial to communities, researchers and institutions alike. Visiting researchers should give tools, techniques and training that communities can use themselves to be better equipped to establish full research partnerships. The community provides researchers with knowledge and skills that serve to increase cultural competence in designing and implementing research projects. In this sense, both sides benefit by having capacity built.

Ethics considerations should be discussed and agreed upon with community leaders, including the Band Council, Elders, health professionals and also the study participants themselves. This should be part of the initial research design, and discussions about ethics should help define the research agenda. As much as possible, the goal should be to reach consensus on both the research objectives, and the ethical application of those in the community.

> Mike Patterson*: I begin sharing the (anonymized) data with research participants, RAs and other community members early on in our projects, including discussions regarding possible authorship. Through this process, decisions about how to best continue the research are grounded in community experience. People are not always keen to get involved, though. For instance, elected officials and health professionals often do not have time, or interest, to be involved in all projects in the community. Researchers should consider when and how to engage already overworked frontline workers, so as not to strain but to improve community resources.*

EXAMPLES OF ABORIGINIAL PROTOCOLS

Akwesasne is a leader in the development of Aboriginal research ethics codes. Working with Elders, three Band Councils, universities such as Harvard and the University of Ottawa, and health professionals, the community is constantly defining and refining its ethics priorities. A watershed document was the *Protocol for Review of Environmental and Scientific Research Proposals* (1996), which calls for: "Empowerment" of both researched and researcher through a "good research agreement developed by both the community and the researcher [...] where application of the research as a useful instrument of the community is balanced with the researchers need for good science;" "Equity," which is defined as a sharing of resources: "Both the researchers and the community must bring equity to the agreement... Finance or money is only one form of equity. Community knowledge,

networks, personnel and political/social power are other forms of equity useful to the project;" and "Respect," meaning that "the researchers and the community must generate respect for each other. Respect is generated by understanding each others social, political and cultural structures... Cultural sensitivity[9] training for the researchers and community awareness presentations will help develop a mutual understanding of the research process."

> *To these the authors would add the concept of trust through effective knowledge transfer: Research processes and procedures must be well explained and understood from a community perspective; not to do so can lead to situations of not trusting the partnership. This can ultimately lead to a slower than normal research process, or an ending of a research partnership agreement.*

In Kahnawake, an extensive code of research ethics was developed involving three partners: 1) the community, represented by an advisory board drawn from the local Mohawk hospital and school board; 2) the community researchers themselves; and 3) representatives from two universities. The Kahnawake Schools Diabetes Prevention Project developed its "Code of Research Ethics", emphasizing that the community is a full partner in all aspects of research, detailing the obligations of academic researchers, community researchers and community partners, and providing authorship guidelines for communicating results to the community and for publication (Kahnawake, 1996).

The "Mi'kmaq Research Principles and Protocols" call for an ethics 'Watch' to review "all research conducted among Mi'kmaw people and maintain control over all research processes" (Mi'kmaw Ethics Watch Committee, 2000, ¶6). There is also an extensive list of obligations and protocols for researchers, beginning with the understanding that "All research on Mi'kmaq is to be approached as a negotiated partnership, taking into account all the interests of those who live in the communities. Participants shall be recognized and treated as equals in the research done instead of as 'informants' or 'subjects'"(¶2). The obligations to researchers also include keeping community members informed in their own language, and delivering research skills to the community where appropriate.

Many First Nations, Inuit and Métis community research models are based on community development, needs assessments, and traditional knowledge methodologies. It is important for outside researchers to understand how communities see and approach research. Community development has been the predominant research approach which centers decision-making at the community level. *A Community Guide to Protecting Indigenous Knowledge* (Brascoupé & Mann, 2001) illustrates how a community development model, which is participatory and utilizes traditional knowledge, can protect a community's knowledge.

CAAN has also developed its own protocol that is used extensively across all its research projects, whether community initiated or not. This document, *Principles of Research Collaboration* acknowledges the importance of "incorporating cultural values and perspectives into the research process" (p. 1). Where the guiding principle is always striving for a significant degree of consensus among research team members, the document outlines the importance of the right to self-determination in research: that Aboriginal participation is meaningfully equal; that the community be involved in the design of a study; that there is a balance between academic/community interests; that ownership of data be shared among members of a research team; and likely most important, the research team "agrees that it may be necessary for Aboriginal community members (investigators and participants) to seek advice and support from community elders and other community leadership" (p. 3). It also insists that the 'Aboriginal problem' not be sensationalized, but balanced with more positive aspects.

> Randy Jackson: *Once data is cleaned of identifying information, CAAN also has a process where data is shared with members of a research advisory committee. Members often share important information with respect to interpretation and offer advice with respect to treatment of potentially*

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[9] The call today for cultural competence, not just sensitivity. Being sensitive to another's culture is one thing – cultural competence is an entire higher level skill set that implies an ability to effectively function in another culture that is not one's own.

sensational research findings. Beyond this, research advisory committees can and have offered suggestions that guide community dissemination and potentially stimulate research uptake.

CHALLENGES TO THE KNOWLEDGE BROKER

Adherence to the emerging Aboriginal research ethics guidelines will be a challenge, particularly for researchers acting as brokers of knowledge between the two worlds, and among all participants in the circle. First, the process involves a complex set of negotiations among researchers, community members, Elders, Band Councils, institutions, and other stakeholders, each with their own protocols and expectations. Those wanting to conduct research in Aboriginal communities will need to consider the interests of all concerned, and develop strategies jointly with the community, which can complicate the REB process. Further complicating this is the fact that there is no consistency among university REBs with regards to issues raised in the OCAP guidelines. As well, enforcement of REBs' existing paradigms is inconsistent from institution to institution, and committee to committee.

With regard to issues above, part of a researchers' job is to sensitize the REB to cultural differences with regard to ethics. It is a daunting task, as the REB relies on its 'institution' of protocols, but the members of ethics committees (the ones to be informed) tend to come and go. REBs need to be made aware of the unique situation of Aboriginal people in Canada. This sensitization is also necessary for those working with other similarly stigmatized or marginalized groups, and experience with new Aboriginal research paradigms may help open the door to this.

Cultural competency should be required to judge Aboriginal research projects. Culturally biased university ethics procedures (i.e., based on Western or Eurocentric worldview or on biomedical models) cannot serve Aboriginal communities. In other words, "ethical research must begin by replacing Eurocentric prejudice with new premises that value diversity over universality" (Battiste & Youngblood, 2000, p. 133). Further to this agenda, an improvement would be to see ethics reviews being done by Aboriginal communities with universities offering reciprocity (rather than the other way around), or the development of Aboriginal REBs at universities.

The researcher today must engage in a complex, but rewarding, discussion of needs and perspectives involving key community members, research participants, and health, educational and/or government organizations. This involves research into (and possibly involvement in) the participating community's culture, language and traditions, before the research project proper can commence. It is acknowledging the reality that each Aboriginal community, and each project, is different, and that each situation requires the mutual respect and concern that can only be generated by sharing complimentary cultural differences. We should "engage an ethical space for a dialogue between Indigenous people and Western scientists [using] double-door entry [by receiving] approval from the community as well as the university [through acknowledgement of] Indigenous theory and method" (Battiste, 2006).

This decolonizing of the research process on the part of the researchers, communities and REBs promises increased culturally coherent research with richer data and more utility (through the mutually reflexive process), real benefits to the communities involved, and a sharing of knowledge that will enrich all of society. Rather than "research Aboriginal communities to death," it is time for researchers, academics and REBs to support processes that research Aboriginal communities to life.

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APPENDIX A

Principles of Research Collaboration

Between
The Canadian Aboriginal AIDS Network
And
[INSERT NAMES]

PARTIES
This document constitutes a Principles for Research Collaboration (PRC) between [INSERT NAMES] (investigators) and the Canadian Aboriginal AIDS Network, a national non-governmental organization dedicated to providing, support and advocacy for Aboriginal People living with and affected by HIV/AIDS regardless of where they reside.

The Canadian Aboriginal AIDS Network will participate as a member of the research team under the terms identified below through [INSERT NAMES].

The above listed individuals constitute the research team. Additional members may join in signing this PRC and participate as members of the research team once all members (listed above) have agreed.

PURPOSE
The purpose of this PRC is to establish a set of principles that guide the conduct of the research projects, *"[INSERT PROJECT TITLE]"* In short, this agreement acknowledges the importance of incorporating cultural values and perspectives into the research process.

RECORDS
The Principal Investigator (PI) or project coordinator will coordinate all administrative matters relating to the above named research project. The PI or project coordinator will provide each member of the research team with notes of meetings, including decisions made, within a reasonable time frame.

ETHICAL CONSIDERATIONS
Ethical codes of conduct for research in Aboriginal communities have been articulated in the *Tri-Council Policy Statement*. However, each member of the research team collectively shares the responsibility for raising ethical concerns and issues. Ethical dilemmas are resolved on the basis of the research team striving for a significant degree of consensus.

DURATION AND AMENDMENTS
This PRC will be in effect throughout the entire research process, from the development of research questions through data collection and analysis phases into dissemination of findings. This PRC can be amended upon mutual consent by members of the research team.

PRINCIPLES: OWNERSHIP, CONTROL, ACCESS AND POSESSION
The research team acknowledges and supports the principles of ownership, control, access and possession as outlined below:

- Members of the research team acknowledge and respect the Aboriginal right to self-determination, including the jurisdiction to decide about research in their communities. In doing so, the research process shall be built upon meaningful engagement and reciprocity between the research team and Aboriginal communities. Further, the research team agrees they will strive to respect the privacy, dignity, culture and rights of Aboriginal peoples.

- The research team will strive to include meaningful and equal participation from Aboriginal community members. Therefore, the parties agree they will be jointly and equally involved from beginning to end in the research process, from research question formulation, though data collection, analysis and into dissemination of research findings related to the above named project.

- The research team may also strive to demonstrate this support by obtaining and attaching letters of support from Aboriginal community leadership at the local level who may assist as either a member of a research advisory committee or in providing assistance related to the recruitment of participants. Primarily, the task of negotiating letters of support from local Aboriginal communities resides with the Canadian Aboriginal AIDS Network.

- The research team agrees that they will collectively make decisions on research questions, in data collection, interpreting results, in drafting research reports and in dissemination of findings. In other words, the PI will not present a completed research design for approval but involve all other members of the research team in the process.

- The research questions must not only reflect academic interests but strive to ensure that the research is also relevant and beneficial to Aboriginal communities.

- In dissemination strategies to Aboriginal communities, the research team agrees that the language and manner of sharing research will be appropriate.

- The (purpose of) research project will be explained to all stakeholders (participants and Aboriginal community members) in a language that is appropriate to the Aboriginal community. Likewise, the research team will explain potential risks and benefits in a similar manner.

- The research team agrees they will not sensationalize problems in Aboriginal communities. Rather, they will strive to present a balanced portrait that also focuses equal attention on more positive aspects. As such, the research team understands that they will collaboratively prepare draft findings prior to submission for publication or presentation. The parties agree to review findings in a timely manner (e.g. two months).

- Given that all members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation, any one member of the research team may not, particularly once initial dissemination has occurred, further analyze, publish or present findings resulting from the above mentioned research project unless the entire research team reaches a consensus.

- The PI is responsible for maintaining the integrity of all data collected, such as storing participant consent forms, etc. However, once privacy and confidentiality of participants has been demonstrated, data sets in the form of SPSS or QSR*N6 (NUD*IST) computer files may be shared with all members of the research team. In cases of disagreement over transfer of data sets (as described above), the research team will strive to achieve a significant degree of consensus.

- The research team agrees to provide meaningful and appropriate research capacity-building, as indicated by Aboriginal community participants.

- The research team agrees that Aboriginal communities have the right to follow cultural codes of conduct and community protocols. However, rather then end a research relationship, in situations were Aboriginal community members are in disagreement, the research team will strive to resolve conflict towards achieving a significant degree of consensus.

- The research team agrees that it may be necessary for Aboriginal community members (investigators and participants) to seek advice and support from community elders and other community leadership.

AUTHORSHIP

Criteria outlined by Huth (1986) will be used as guidelines for authorship of publication based on the findings of the research. The criteria recommend that: (1) all authors must make a substantial contribution to the conception, design, analysis, or interpretation of data; (2) authors must be involved in writing and revising the manuscript for intellectual content; and (3) authors must approve the final draft and be able to defend the published work. Those who have made other contributions to the work (e.g. data collection without interpretation, etc.) or only parts of the above criteria should be credited in the acknowledgements, but not receive authorship. Further,

- Research project staff may participate as authors provided that they fulfill the criteria outlined above.
- All members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation. Any one member of the research team may further analyse, publish or present findings resulting from the above-mentioned research project with the agreement of the Principal Investigator and the other research team members.
- The explicit permission of an individual or organization must be sought prior to acknowledging their contribution in a paper or presentation.
- A research team member or a partner may chose to include a disclaimer if they do not agree with the content or views presented in a publication.

IN WITNESS WHEREOF, the parties hereto have executed this agreement.

(Date)	_(Signature)_

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A number of sources were consulted in preparing these Principles of Research Collaboration. The Canadian Aboriginal AIDS Network acknowledges the contributions of the following sources.

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