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Shifting from Reading to Questioning: Some Thoughts around Ethics, Research, and Aboriginal Peoples

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During the summer of 2002, we worked on a project exploring issues surrounding ethics and research with Aboriginal people. As we reviewed a number of articles published in this area, our library and Internet searches were accompanied by multiple conversations. Within these conversations we often wondered about the written words, words primarily written by academics, rather than community members. In the written documents, many authors identify some of the complexities and ethical issues that are equally exciting, frustrating and engaging. Overall, however, there is a dearth of published and readily accessible discourse on ethics in the context of research and Indigenous communities, perhaps reflecting the early stage of critically contemplating the ethical implications of research within Aboriginal communities.

During the fall of 2002 we took the class *From Written Text to Oral Tradition* at the University of Alberta with Dr. Stan Wilson. Throughout the course we often thought about our ethics project and began to recognize the origin of our struggles with the project. We returned to our past conversations and writings with new insights, we wondered about ethical guidelines and are no longer certain they provide us with answers or appropriate frameworks for ethical research. We began to ask: What do Aboriginal communities perceive to be respectful research? How do they envision the research process to be unfolding? How do they conceptualize possibilities of engagement with researchers? How do we honour oral traditions? How could we honour who people are, and who they are becoming? Although we still do not have answers to many of these questions, this paper is the beginning process of reviewing some of the relevant literature, and of expressing our own views and questions about research, relationships, and possibilities.

Existing Ethical Guidelines

Some of the most comprehensive ethical guidelines in research are found within the policy statements and documents of national and international organizations. The issues most commonly addressed regarding communities include: consultation, the consent process, involvement in the conduct of research, access to data and samples, and dissemination of findings (Weijer 1999).

> *How can research be so fragmented and compartmentalized? Is the process not much more fluid and circular?*

Specialized documents, which focus on a particular issue, were developed as the need for increased protection for Indigenous peoples emerged (National Aboriginal Health Organization 2002). Arguably, the concerns of Indigenous peoples in relation to research are not new and may indeed be multiplying for several important reasons. Some of these reasons include: increased access to isolated communities; increased knowledge of the potential negative consequences for Indigenous communities involved in research (Lujan 1989, O'Neil et al. 1998, Weijer and Emanuel 2000); increasing complexity of research and the creation of new fields of research; increased participation in the political sphere supporting new policy development such as the Native American Graves Protection and Repatriation Act (Simpson and Jackson 1998); increased awareness of the value of intellectual knowledge and resources that Indigenous peoples possess (Posey, Dutfield and Plenderleith 1995); and potential for increased monetary gains for Indigenous peoples regarding intellectual property (Battiste 2000, Laird 1999).

Would these problems persist if we paid attention to relationships? What if we attempted to listen on a deeper level and engaged with others in a respectful way?

The controversial nature of consent for all participants of research is reflected in the vast amount of discourse that exists on the subject and the detailed attention paid to this issue within existing ethical guidelines (Medical Research Council of Canada et al. 1998). For Indigenous peoples, the consent process is of paramount concern due to past negative experiences and the misappropriation of Indigenous resources (National Aboriginal Healing Foundation 2000, O'Neil et al. 1998, Scott and Receveur 1995, Stager 1994). Areas of potential concern specific to Indigenous peoples include: differing interpretations of confidentiality issues (Ellerby et al. 2000); competing interests within communities or groups (Royal Commission on Aboriginal Peoples 1993); the role of family and community in individual decision making (Gostin 1995); and the need to obtain prior informed consent which entails a full disclosure of research reasons, procedures, risks, and implications before permission is granted by communities or individuals (Piquemal 2001, Posey and Dutfield 1996). Additional issues of consent for Indigenous communities involve emerging concerns in relation to traditional knowledge

and traditional resources due to the potential for monetary gain (Posey et al. 1995).

> *Are any of these different interpretations of consent related to oral cultures, to the multiple ways of telling stories and being in the world and understanding the world around us? Do we not have to continuously consent, to be attentive to the changing relationship? Can we assume that because we talk to each other that we want our stories interpreted and taken away to be retold?*

Despite recognition that Aboriginal communities need increased protection, many ethical guidelines and codes of ethics are based on principles that are derived from a common value-base. Yet, the value-base common to Aboriginal peoples, which differs from the value-base common to most research scholars, is rarely considered during the exploration and implementation of ethical issues.

> *Who decides on the values on which most research is based? How can the values of Aboriginal peoples and communities be acknowledged? Are we always aware of our own values? How can outsiders understand the values embedded in oral traditions — values that are rarely explicitly stated?*

The following points are a summary of key thoughts around current ethical guidelines:

- Researchers and scholars rely on ethical review committees, institutional review boards, and other national mechanisms to protect human subjects during the activities of research. There is an over-reliance on published literature and experts by ethical review boards, with little direct input from Aboriginal communities.
- There is recognition that a critical review of the processes of institutional and ethics review boards would be useful to determine their impact on and relevance to research with Aboriginal peoples. In addi-

tion, the published discourse on ethical guidelines rarely differentiates between the schools of thought on ethics and their impact in relation to research with Aboriginal peoples.

- The lack of published discourse regarding "Codes of Ethics" may indicate the controversial nature of these documents and reflect the limited power to ensure ethical conduct that these documents possess.
- The discourse on ethical guidelines and practice needs to move away from rhetoric and provide evidence of its application to research with Aboriginal peoples. Further, the literature primarily offers critiques of existing ethical guidelines with limited sources that focus on relevant approaches to research with Aboriginal peoples.
- Researchers and scholars often neglect to recognise the important role that developing relationships plays in ensuring protection to Aboriginal communities involved in research. As well, researchers generally possess a limited understanding of the potential for harm to Aboriginal communities or individuals involved in research.
- Researchers often neglect to seek direction from Aboriginal communities regarding the application of ethical guidelines or conduct.
- Mechanisms to enforce ethical guidelines need to be put in place in order to provide Aboriginal communities with recourse in the event of misconduct. These mechanisms need to be extended to include issues of accountability such as negative consequences to Aboriginal communities. In addition, mechanisms that address issues related to the integrity of research, such as results that reflect Aboriginal perspectives, need to be developed.

How can we really ensure ethical behaviour by researchers and research participants? If it is based upon relationship, can we even have ethical guidelines? Who then decides when something has gone wrong, when behaviours are harmful and hurtful? How do we negotiate this in relationships with others? Can we, as researchers, understand the other without spending time within Aboriginal communities?

Challenges to Existing University Ethical Guidelines

Acknowledging conflicting arguments in the role that ethical guidelines play in the research process and the protection of Aboriginal peoples is important to ensuring that researchers and communities have all the facts. First, there is debate on the practical value that these guidelines possess as mechanisms of enforcement, such as contractual agreements, which are thought to be in direct contradiction to Indigenous societies (Hedley 1986). Second, the use of ethical codes of conduct may be incompatible with the rules of behaviour for many Indigenous peoples, such as the concept of non-interference with another individual's behaviour (Brant 1990). Third, some researchers feel that ethical guidelines should not be able to put limits on the acquisition of knowledge as long as there is a balance between moral acceptability and potential risk (Paula 2001).

> *So what limits knowledge? And who then owns the knowledge? How too do we acknowledge the diversity amongst and between Aboriginal communities?*

Ethical guidelines are often written specifically for researchers and professionals, applied rigidly and mistaken for the law (Little 1999). Instead of guidelines or codes of ethics for researchers and professionals there needs to be recognition that ethics applies to all peoples. Indeed, ethical guidelines and decisions made by Ethics Review Boards are more concerned with meeting the needs of the academic and scientific community, than protecting individuals or communities.

In addition, it has been noted that Ethics Review Boards have limited understanding of Aboriginal peoples' perspectives on the potential risks and benefits of particular research. As well, there is no clear and common language for ethics reviews on Aboriginal specific issues (Little 1999). Furthermore, Young (1995) points out that research ethics often refers to a smaller set of issues, which exclude such issues as setting research priorities, ownership and control of the research process, and outcome and dissemination. Yet, issues that are of main concern within Aboriginal communities are: proper consul-

tation, community involvement, and ownership of data (Scrimgeour 1993, Wax 1991).

Is this the same in every community? Who will come forward to claim these concerns? Will addressing these concerns really resolve the ethical issues? Or will other issues surface? How will the data be used once ownership is determined? Is there value in transmitting the findings orally? How will they be talked about amongst community members?

Positioning of Research

Successful research experiences for the Aboriginal community often involve a shared partnership of collaboration between the researchers and the community. Further, elements of true collaboration include engaging with Aboriginal communities to discover potential areas of research, developing research agreements or contracts that allow for consultation and resolve of emerging concerns during all aspects of the research, involvement of Aboriginal peoples as co-researchers and co-authors, opportunities to analyze the data and joint consultation in determining the findings, equal rights to the dissemination of findings encompassing all written and oral presentations, ownership rights to the data and findings, and opportunities to share in the responsibility of ethical conduct.

What is true collaboration? By what standards do we measure it? Does collaboration mean to give up certain values? Or is it about giving up or sharing certain rights? Is the concern to gain more knowledge, and who will benefit?

Research with Aboriginal communities encompasses many challenges and opportunities. The definitions of community within the literature are vague and tend to ignore the diversity that exists within and among

Aboriginal groups. This often produces results that are too generalized or which perpetuate the stereotypes associated with Aboriginal peoples.

How do you break the stereotypes — particularly if people don't come to listen and be attentive? Maybe part of the answer is in oral traditions? How do we revitalise them? Do people within communities listen to and acknowledge the stories? How do we know?

One of the more salient issues discussed to varying degrees within the published and accessible literature is the concept of respect. It is clear from a review of the published literature that much of the scientific research community possesses only a limited understanding of the concept of respect in relation to Aboriginal peoples. That this level of understanding needs to be nourished and encouraged to develop is evident in the lack of discourse that details or envelops the attributes of respect towards a culture whose many practices and traditions are based on principles of respect. Further discourse, which explicates the central role of respect within Aboriginal society, may lead to increased mutual understandings of ethical research.

What is respect? How do we learn it? Do we carry the respect with us?

Consultation with Indigenous communities encompasses all phases of research and identifies the following areas of potential concern: the development of research areas deemed beneficial by the community (Royal Commission on Aboriginal Peoples 1993); defining the research practice and project (Battiste 2000); the need for ongoing communication (Holmes et al. 2002); the use of relevant research paradigms (Scott and Receveur 1995), and; the development of practices that safeguard the liberty and integrity of Indigenous peoples (Greely 1996).

Involvement in the conduct of research is deemed one of the most effective ways in which to ensure that the rights and perspectives of Indigenous communities are acknowledged and valued (Council of Yukon First Nations 2000). Areas of potential concern include the following: lack of education should not prevent community participation (Association of Canadian

Universities for Northern Studies 1998); lack of involvement discounts the value of Indigenous perspectives (Blanchard et al. 2000); lack of direct input from Indigenous communities runs the risk of paternalistic decision making and the imposition of euro-centric values on Indigenous perspectives (Battiste 2000, Grenier 1998); and the transference of skills to Indigenous communities should occur as much as possible (Royal Commission on Aboriginal Peoples 1993). As well, limited or no understanding of Indigenous languages changes the interpretations of the findings (Royal Commission on Aboriginal Peoples 1993), limited access to data and samples creates the potential for concern in relation to ownership of data (Janke 1997), uses of the data which differ from the initial reasons for collecting the data, monetary gains for non-Indigenous peoples (Simpson and Jackson 1998), and the potential for loss of traditional knowledge from Indigenous communities (Battiste 2000).

> *Where does all this place Aboriginal youths? How do they feel about some of the research endeavours? How do they understand respect? Do they value oral traditions? How do they come to understand them? What part do they want to play in research?*

Dissemination of findings is an area that warrants special consideration by researchers (Laird 1999, O' Neil et al. 1998). Concerns may include appropriate patterns and meanings of the findings (Masuzumi and Quirk 1993), ownership of data (Simpson and Jackson 1998), publication and copyrights (Brown Childs 1998), and First Nations' worldviews which cannot be applied to all First Nations' communities (McCormick 1998).

It is also of critical importance to avoid imposing euro-centric values on the representations of Aboriginal peoples in relation to research findings. Past historical accounts of Indigenous peoples have often placed them in a European context with European values (Red Horse et al. 1989), rather than in the natural world with their own cultural understandings (Fixico 1998).

Methodologies

The process of research cannot easily be separated from the methods chosen to address a specific research question (Moewaka Barnes 2000). In as much as the relationships between researchers and communities are diverse,

methods of research need to reflect diversity, emphasize experience, and be able to explore new meanings (Moewaka Barnes 2000). In the past, research methodologies have rarely recognized or valued the different or alternative ways of knowing which Aboriginal peoples possess and often discount their community stories or accounts that reflect these epistemologies.

> *What values are reflected in the choice of the research methodology? How does the methodology reflect who you are — you as an individual, as a member of a family and community, as an Aboriginal or non-Aboriginal person? Maybe we have to ask, how is relationship reflected in the methodology? Maybe it is more — how are the multiple ways of relationships and understandings reflected? Can we separate method from methodologies, or methodology from being in the world?*

Therefore, particularly important is that the methodology chosen is reflective and congruent with the cultural norms and values of the community (Weaver 1997). Greater autonomy has to be given to Indigenous people and multiplicity, rather than scientific rigidity, needs to be attended to by the researcher (Agrawal 1995). For instance, traditional disciplines such as anthropology need to embrace new perspectives and develop new research methodologies (Sillitoe 1998, Elisabetsky 1991). Integrating research-based knowledge with community-based knowledge will not only lead to increased levels of success, but also enrich strategies and research methodologies (Moewaka Barnes 2000).

Weber-Pillwax (1999) discussed the following key issues which are important to consider in the development of Indigenous research methodologies: all forms of life must be respected as being related; research must benefit the community; research must be grounded within the reality of lived experience; Indigenous methodologies must provide the foundation for theoretical developments; transformation and process are central elements of research; and the integrity of Indigenous peoples or communities must be respected.

Throughout any research project the diversity amongst and within Indigenous communities must be acknowledged and honoured (Cunningham 2000) while the priorities of the community must be central to the research (O'Neil et al. 1998). Moreover, research methodologies that reinforce unequal power relationships should be avoided.

> *Does the research benefit the community in ways that are meaningful and relevant to the community? Thinking about the changes that occur during research, are we, as researchers, returning with the findings to the community, and do we engage in continuous reflection? How do we acknowledge that all participants involved in the research have changed?*

Regardless of the methodological choice or approach to research, questions about the motivation of researchers and communities to engage in research need to be addressed. Reasons to undertake the research may include the possibility and desirability of change (Moewaka Barnes 2000), to build local capacity (Black 2000, Mohatt 1989, Chrisman 1999, Conway et al. 2000), to empower communities and individuals (Bishop 1994, St. Denis 1992), or to raise consciousness (Kurelek 1992).

> *How do we acknowledge the diversity within the community? Can we hear the voices of the Elders and of the youth?*

Researchers need to be aware of the historical, social, and political issues affecting Aboriginal communities in order to avoid the continuous victimization of Aboriginal peoples and support the development of research methodologies which are liberating (Wright 1988). Furthermore, research endeavours should be critically evaluated in an attempt to avoid the assimilation of Aboriginal peoples into the larger society and instead to place value on indigenous cultural, historical, and social understanding (Alia 1998, Stubben 1997).

Are we aware of our agendas and the cultural baggage that we carry with us? What is our obligation toward honouring other cultures? How can we recognize and resist our own assumptions?

It is important to recognise that the collaborative endeavour must not stop with the collection of data; rather, Aboriginal peoples must have access to data along with opportunities to interpret and analyse the data (O'Neil et al. 1993). Engaging Aboriginal communities in the interpretation and analysis of the data can safeguard against the misrepresentations of Aboriginal culture (Deloria 1991) and avoid the potential harmful consequences that these misrepresentations may pose (Carrese and Rhodes 1995). There is a clear and increasing need to truly co-interpret and co-author research findings with research participants (Lassiter 2001).

Can we lay our interpretations alongside each other? How do we honour the multiple understandings — like it is done in oral traditions? Is the written text of research able to articulate multiple understandings?

Researchers do not have the automatic rights to publication in many Aboriginal communities (Miller and Rainow 1997). Aboriginal communities are frequently engaging in research in order to gain increased understanding and knowledge that will benefit their own communities, rather than just the researchers and policy developers (Huntington and Fernandez-Gimenez 1999), and which will not be used to profit industry (Elisabetsky 1991). In the dissemination process, data must be made available to communities in accurate and culturally appropriate forms and communities must have a clear understanding of the limitations of research findings (van Holst Pellekaan 2000). Several authors discussed the challenges and opportunities regarding the dissemination process (Humphrey 2000, Kimberly Aboriginal Health Workers 1992). Particularly important is that the knowledge is grounded in local, detailed, and culturally specific events (Weaver 1997, Winch and Hayward 1999, Ryan and Spence 1978). As well, Aboriginal peoples should be entitled to name or identify themselves and their communities (Thomas and Jacobs 1999).

How do we construct the "other" in the story? What stories will be told about us as researchers?

Dissemination strategies however must not only be project specific, but should also provide communities with opportunities to learn about Indigenous and other ways of knowing (Hooley 2000). Additional avenues for the dissemination of research information may be accessed through schools, local libraries or other accessible depositories (Arctic Research Consortium of the USA 1998, Hooley 2000, Wax 1991). It is also important that the knowledge gained is integrated into community planning activities (Haeusler 1995), supports communities in land claims and other court cases (Hoare et al. 1993), and is capable of communicating Aboriginal issues to the government (McNab 1986). Moreover, adequate financial and human resources are needed to act upon findings from research endeavours in order to meet community expectations and requirements. As well, Aboriginal communities need funding to support the conduct of their own research, thereby fostering possibilities for the creation of a foundation for research activities that are trustworthy and credible (O'Neil et al. 1998).

Does the research itself legitimize the telling of stories or the oral traditions? Do we only get together within the communities to tell them under the disguise of research?

Positioning of Relationships

Published accounts of many research studies often focus on the outcomes of the research, to the neglect of the processes involved. In addition, few reports provide an account of the ways in which the findings benefit Aboriginal communities or follow up with articles that offer possible solutions to solve identified concerns or problems.

Why do we often neglect the process in our research? Why does the search focus on outcomes? When does the telling and engaging with become as important as the outcome?

Research is always process oriented and those involved need to be reflective both of the process and the relationships that are established throughout the research. Casteel (1996), for example, sees informed consent as an ongoing dynamic process. While consent has to be continuously negotiated, there is also a need to acknowledge that both researcher and participants are affected by the research. Guidelines do not adequately address the complexity of the research process and the relationships that are established when engaging in research are not easily replicated (Hermes 1997).

It seems our understanding is beginning to shift, away from the guidelines to the processes and the relationships. What has precipitated our understanding and shifting? Why did it happen for both of us at the same time? Learning seems to be forever evolving — how then can we ever write a final research report?

There have been almost no enquiries which examine the forms and processes of research when working with Indigenous communities. However, there is recognition that flexibility and humility are important elements in research and that the best approaches involve negotiation with Indigenous communities. In his discussion of the salient features of research with Aboriginal peoples, John (1990) suggests that research with Aboriginal peoples takes more time than research with non-Aboriginal peoples as there needs to be a constant process of negotiation. As well, the gatekeepers within each community are often ubiquitous.

Kirkness and Barnhardt (1991) recommend four general guidelines for higher education with respect to Aboriginal peoples, which could also guide the research process with Aboriginal communities:

1. the cultural integrity of First Nations peoples must be respected;
2. the experience must be relevant to First Nations perspectives and experience;
3. the established relationship must be reciprocal, and
4. responsibility is practiced within the established partnership.

Kirkness and Barnhardt seem to make sense with their notion of shared responsibility, of listening and telling in mutual recognition that each one of us carries knowledge and brings understanding.

Respect

Respect for cultural integrity is based upon the recognition that Aboriginal peoples have different ways of knowing (Bramwell and Foreman 1993), different value systems (Kavanagh et al. 1999), do not share a common moral vocabulary or a common vision of the nature of human beings (Wax 1991), and place a much greater role on spiritual values. Care has to be taken not to impose euro-centric values such as individualism, autonomy, self-determinism, and privacy. Differences in ethical understandings can be seen as differences in local knowledge, neither being exclusive of the other (Christakis 1992). It is therefore of utmost importance to explore and negotiate differences in our interpretations of ethics (Christakis 1992).

Respect has been identified as one of the key elements of research with Aboriginal peoples and communities (Assembly of Alaska Native Educators 2000, Brown Childs 1998, Hernandez-Avila 1996, Hermes 1997, Moewaka Barnes 2000). Respect must be shown for both Aboriginal communities and individuals (Hernandez-Avila 1996). The concept of respect includes the idea of reciprocity (Hermes 1997), listening, and a continuous re-evaluation of the research process and outcomes (Haig-Brown 2000). Listening refers not only to the voices of experts, but to everyone's voice (Haig-Brown 2000), thereby creating an atmosphere where the local knowledge of individuals and communities is honoured.

Respecting local knowledge and experience not only attempts to protect cultural knowledge from exploitation, but also acknowledges that outside researchers can only gain a rough insight (Moore 1997). In as much as research is about the creation of new knowledge, there is a recognition that research is also about forming and sustaining relationships (Haig-Brown 2000) in which authenticity and identity are primary elements (Hernandez-Avila 1996).

However, some researchers become more sensitive to this issue once they have been exposed to Indigenous practices and value orientations (Kavanagh et al. 1999), enabling the development of mutual attitudes for trust and respect (Hanna 1999).

Respect has to become one of the key words, although we have not completely understood its complexity. Like oral traditions, the concept evades clear definition, it is forever shifting.

Reciprocal Relationships

Reciprocal relationships are marked by extensive community consultation in which communities often become the co-researchers. Boston et al. (1997) explored the meanings which Aboriginal people attribute to diabetes and provide a good example of how research, based on the principles of reciprocity, can be successful. Furthermore, reciprocal relationships support an acknowledgement of community contributions, shared power, value for respect and diversity, as well as enabling researchers to provide recruitment and training opportunities for local peoples (Kone et al. 2000, Lockhart and McCaskill 1986). Reciprocal relationships, which are marked by collaboration, have the potential to narrow the gap between the academy and the community (Lassiter 2001).

Initiating collaborative research endeavours is made possible through asking questions that seek to understand local concerns (Bishop 1994, Lockhart and McCaskill 1986). These may include multiple competing priorities within communities (Miller and Rainow 1997), the Aboriginal community's request for research results that have immediate relevance and applicability (Miller and Rainow 1997), and the abilities of the research to provide directions for practical action. Researchers need to remain flexible throughout the research process and engage in constructive conversations while building strong interpersonal relationships (Brown Childs 1998).

Lengthy periods of engagement and consultation can lead to strong community connections and bring about friendships which may provide an opportunity for the expression of interest in future research with Aboriginal peoples and communities (van Holst Pellekaan 2000). Collaborative research may alleviate feelings of distrust related to past experiences with researchers. Adopting an ethics of listening may create possibilities for the documentation and discussion of cultural, historical, political and individual differences within the public sphere (Olubas and Greenwell 1999).

The concept of engaging in research *with* Aboriginal communities rather than *on* Aboriginal communities is critical to collaborative research initia-

tives (Kurelek 1992) and leads to research that is performed for and by the Aboriginal peoples (Young 1995). During the collaborative process it is important to address questions of how to balance collective or community interests with individual interests (Sharp and Foster 2002) and to clearly identify who gives consent to research (Wax 1991).

Most importantly, the responsibility for collaborative partnerships is shared between the community and the researcher (Attneave 1989). Both researchers and community members need to discuss relational issues and be reflective of their position. Researchers have to pay particular attention to issues of insider/outsider power and privilege (Haig-Brown and Archibald 1996).

It is like you and me sitting here and trying to have this conversation with Stan when he was in Australia. How do you have this conversation? Does a relationship require people to be present and engaged? Yet, throughout our class we thought much about conversations with trees and places on the landscape, with people who have passed on and who have not yet been born. Maybe we can talk with Stan from so far away. How does this shape our relationship? Yet earlier we have argued that researchers need to be present within communities and peoples lives and now we are talking about something else. How can we explain this shift? Can you ever explain what it is like to talk with ghosts? And how do we know who our audience is? How do we acknowledge them? Where is the relationship in writing?

Conceptualizing Possibilities

An overwhelming majority of the literature gathered on the topic of ethical guidelines in research and indigenous peoples recognizes, supports, and urges the need for Indigenous specific guidelines which provide special protection to Indigenous peoples and communities (Ellerby 2001, Lauderdale

and Oliverio 1995, Macaulay et al. 1999). The following are suggested solutions found within the ethical guidelines of international and national documents:

- Opening up existing ethical and research protocols to reassessment (Royal Commission on Aboriginal Peoples 1993).
- Re-evaluating ethical guidelines to promote further consistency with the research process (Donovan 1997).
- Sharing in the responsibility of ethical conduct by Aboriginal communities and researchers (Hedley 1986).
- Developing clearer parameters for ethical conduct in research (National Aboriginal Healing Foundation 2000).
- Developing Indigenous ethics review boards with equal powers to national review boards or university ethics review boards (National Aboriginal Health Organization 2002).
- Shifting from information gathering to placing emphasis on information sharing in order to encourage relationship building (Manderson et al. 1998).
- Granting financial control of potential research projects to the community involved in the research (Royal Commission on Aboriginal Peoples 1993).
- Requiring the use of research agreements or binding negotiations prior to the ethical approval of research.
- Developing Aboriginal research ethics standards with appropriate and effective mechanisms of enforcement (National Aboriginal Health Organization 2000).
- Inclusion of community people on research ethics review boards.
- Expanding on existing international and national laws to include additional protection for all Indigenous nations in relation to intellectual property rights (Janke 1997, Ledwon 1997).

Further, the potential for protection in issues of research with ethical guidelines is often not guaranteed, especially in the absence of mechanisms for enforcement. The scant avenues of recourse for Aboriginal communities, such as laws which only apply to issues of treaty entitlement and powers of veto that do not extend to Aboriginal ethics review committees, limit the

practical use of ethical guidelines and warrant the review of existing guidelines.

In the recent past, Indigenous and Aboriginal communities have begun to develop their own ethical guidelines for the purposes of research. Examples include the Haida Gwaii First Nations and Mohawk First Nations of Canada, and the Kuna of Panama. Citing past negative experiences and the need to address diabetes within their community, the Mohawk First Nations of Kahnawake participated with research partners in order to develop a code of research ethics (Kahnawake Schools Diabetes Prevention Project 1996). The code of ethics, based on a set of ethical principles, outlines obligations for each partner and addresses all aspects of the research process. Enabling the project to focus on an identified need of the community, this research was designed to benefit the health of the Mohawk and reflects many of the present endeavours of Aboriginal peoples to share increased responsibility toward their own protection in research.

Ethics Review Boards which consist of Aboriginal community Elders, Aboriginal leaders, Aboriginal community members and Aboriginal professionals need to be involved in the development of ethical guidelines and a code of ethics that respects the cultural, historical and social context of Aboriginal communities. As well, ethics review boards need to be more representative of the cultural diversity within and among Aboriginal communities in order to promote an increased understanding of Aboriginal peoples. In addition, such review boards must represent more than ad-hoc committees or subcommittees with limited powers and must share levels of power at least equal to national ethics review councils and university ethics review boards. Moreover, mechanisms of enforcement need to be developed in order to ensure that ethical guidelines are followed throughout the research process. It may also be of great benefit for non-Aboriginal ethics review committees to undergo additional training in order to fully understand ethical issues in research with Aboriginal communities.

The more we read and reflect on these solutions and thoughts, the more questions we have. We have to wonder who takes responsibility for developing these guidelines?

Avoiding Prescriptions

However, these arguments often neglect or omit the perspectives of Aboriginal peoples and therefore lack the insights that Indigenous peoples and organizations possess in relation to these issues. For instance, although there are large amounts of evidence that necessitate the need for research agreements and restrictions on research, such as the common Indigenous experience with colonial research practices, the emphasis that Aboriginal communities place on relationship building often precludes the use of laws as a recourse in many agreements (Battiste 2000, Smith 1997).

Although many of the disciplines and academics of universities intend to have research relationships with Aboriginal peoples, few have sought direct input from Aboriginal communities or Elders in developing codes and protocols. Hence, throughout the published and accessible literature, there is an absence of voices from the Aboriginal community and Elders. Also apparent are the limited numbers of Aboriginal communities or individuals who are co-researchers and co-authors of research findings. Further opportunities for Aboriginal peoples involved in this part of the research process need to be created and the development of ethical guidelines in research with Aboriginal peoples needs to reflect such opportunities.

Perhaps reflecting the need to re-evaluate such codes and protocols in their abilities to be compatible with Aboriginal perspectives is the following recognition by Scott (1996: 751),

> . . . new legal regimes are emerging and the relations between community members and outside researchers are being redefined. As it has become no longer acceptable to conduct research in Indigenous communities without paying attention to the research needs and priorities of the people who live there, a new process of conducting research is emerging.

Clearly, research directions and questions must come from the Aboriginal community. In addition, only research with the potential to benefit the community in meaningful ways should be considered ethical research.

Also, in accordance with the emphasis that Aboriginal peoples place on community, further benefits may be gained through additional discourse on ethical guidelines, which shift their focus from the individual to the community and which expand upon this relationship to include connections between the human and spiritual realms and the environment. There is a lack of

research projects that address or express an understanding of this interconnectedness.

Greater attention needs to be given to the processes of research and to those relationships that are established during the research process. Moreover, there is a limited understanding of Aboriginal peoples' perceptions of what research is and how research relationships should be established and maintained. Perhaps for now, there needs to be richer and deeper discussion in this field and the texts of research relationships and the processes of research. It is of particular importance to encourage and create further opportunities for the increased dialogue between Indigenous peoples and the research community. These opportunities need to occur on both national and international levels in order to support increased understandings of the many issues that affect Indigenous peoples in relation to ethics and research.

Coming to Conclusions

Within the literature, there is an acknowledgement that existing ethical guidelines in research with Aboriginal peoples may be shown to have progressed in relation to an increased awareness of those issues which necessitate special protection in research with Aboriginal peoples. The diverse sources from which the ethical guidelines originate add to the complex nature of this topic and reveal the need for further discourse on ethical guidelines and issues of research with Aboriginal peoples. Also, opportunities to exercise the application of ethical principles and actual ethical guidelines in research with Aboriginal peoples may be more attainable through understanding their content and their potential to provide adequate protection. Moreover, the increased initiative of Aboriginal communities to participate in all aspects of the research process may foster further development of Aboriginal specific ethical principles and guidelines and enable researchers to reach a better understanding of the issues that affect Aboriginal peoples in relation to research.

In conclusion, the assurance of ethical guideline development toward appropriate mechanisms for the adequate protection of Aboriginal peoples during the endeavours of research necessitates a clearer vision of Aboriginal perspectives. As such, we acknowledge that

> any attempt to devise uniform guidelines . . . runs the risk of collapsing ethics jurisprudential diversity into a single "model" that will not fit the values, conceptions, or laws of any indigenous society. (Laird 1999: 4)

It has become evident to us throughout this paper that culturally sensitive ethical guidelines alone are not sufficient to develop research activities that are respectful, relevant, and reciprocal to Aboriginal peoples.

Questions are still remaining and the words and readings only seem to push us towards more questions, not answers. Yet they also push us as we sit here and type these words, to engage with others, to listen carefully and attentively.

References

Agrawal, A.
1995 "Dismantling the divide between indigenous and scientific knowledge." *Development and Change* 26: 413-39.

Alia, V.
1998 "Indigenous peoples and media ethics in Canada." *Cultural Survival Quarterly* 22(2): 48-52.

Arctic Research Consortium of the United States
1998 *Building Partnerships in Polar Research and Education.* Arlington, VA: National Science Foundation.

Assembly of Alaska Native Educators
2000 "Guidelines for respecting cultural knowledge." [Web Page]. 2000 Feb 1; Accessed 2002 Jun 27. Available at: http://www.ankn.uaf.edu/standards/culturaldoc.html.

Association of Canadian Universities for Northern Studies
1998 *Ethical Principles for the Conduct of Research in the North.* Ottawa, Canada: Association of Canadian Universities for Northern Studies.

Attneave, C.
1989 "Who has the responsibility? An evolving model to resolve ethical problems in intercultural research." *American Indian and Alaska Native Mental Health* 2(3): 18-24.

Battiste, M.
2000 *Reclaiming Indigenous Voice and Vision.* Vancouver: University of British Columbia Press.

Bishop, R.
1994 "Initiating empowering research?" *New Zealand Journal of Education Studies* 29(1): 175-88.

Black, J.
2000 "AIDS research developed the First Nations way." *Windspeaker* 17(10): 20.

Blanchard, M., A. McKnight, L. Lui-Chivizhe, D. Wray, K. French, J. Sherwood, S. Galleguillos, and A. Smith, panel members.
2000 "Creating an optimistic future for indigenous research in education: re-visioning both outcome and process." Panel presentation report. In Michelle Blanchard, ed., *Australian Association for Research in Education; The Koori Centre, University of Sydney*. Australia: Australian Association for Research in Education.

Boston, P., S. Jordan, E. MacNamara, K. Kozolanka, E. Bobbish-Rondeau, H. Iserhoff, S. Mianscum, R. Mianscum-Trapper, I. Mistacheesick, B. Petawabano, M. Sheshamush-Masty, R. Wapachee, and J. Weapenicappo
1997 "Using participatory action research to understand the meanings Aboriginal Canadians attribute to the rising incidence of diabetes." *Chronic Diseases in Canada* 18(1): 1-12.

Bramwell, R. and K. Foreman
1993 "Questioning power structures and competitiveness in pedagogy — insights from North American Indian and Philippine pedagogies." *International Review of Education* 39(6): 561-575.

Brant, C.
1990 "Native ethics and rules of behaviour." *Canadian Journal of Psychiatry* 35(6): 534-539.

Brown Childs, J.
1998 "Transcommunality: From the politics of conversion to the ethics of respect in the context of cultural diversity-learning from native American philosophies with a focus on the Haudenosaunee." *Social Justice* 25(4): 143-69.

Carrese, J. and L. Rhodes
1995 "Western bioethics on the Navajo reservation." *Journal of American Medical Association* 274(10): 826-29.

Casteel, J.K.
1996 "The ethics of informed consent among storyteller cultures." In R. Fortuine, ed., *Circumpolar Health 96*. Anchorage, Alaska.

Chrisman, N.
1999 "Community partnership research with the Yakama Indian Nation." *Human Organization* 58(2): 134-141.

Christakis, N.A.
1992 "Ethics are local: Engaging cross-cultural variation in the ethics for clinical research." *Social Science and Medicine* 35: 1079-91.

Conway, K., M. Tunks, W. Henwood, and S. Casswell
2000 "Te whanau cadillac — A waka for change." *Health Education and Behavior* 27(3): 339-50.

Council of Yukon First Nations.
2000 *Traditional Knowledge Research Guidelines: A Guide for Researchers in the Yukon.* Yukon: Council of Yukon First Nations.

Cunningham, C.
2000 "A framework for addressing Maori knowledge in research, science and technology." *Pacific Health Dialog* 7(1): 62-69.

Deloria, V.
1991 "Commentary: Research, redskins, and reality." *American Indian Quarterly* 15(4): 457-469.

Donovan, R.J. and R. Spark
1997 "Towards guidelines for survey research in remote Aboriginal communities." *Australian and New Zealand Journal of Public Health* 21(1): 89-95.

Elisabetsky, E.
1991 "Sociopolitical, economical, and ethical issues in medicinal plant research." *Journal of Ethnopharmacology* 32: 235-39.

Ellerby, J.
2001 *Working With Aboriginal Elders.* Second ed. Winnipeg, Manitoba: Native Studies Press.

Ellerby, J.H., J. McKenzie, S. McKay, G.J. Gariepy, and J.M. Kaufert
2000 "Bioethics for clinicians: 18 aboriginal cultures." *Canadian Medical Association Journal* 163(7): 845-50.

Fixico, D.
1998 "Ethics and responsibilities in writing American Indian history." In D.A. Mihesuah, ed., *Native and Academics.* London: University of Nebraska Press, pp. 84-99.

Gostin, L.O.
1995 "Informed consent, cultural sensitivity, and respect for persons." *Journal of American Medical Association* 274(10): 844-845.

Greely, H.T.
1996 "Genes, patents and indigenous peoples: Biomedical research and indigenous peoples' rights." *Cultural Survival Quarterly* 20(2): 54-57.

Grenier, L.
1998 *Working With Indigenous Knowledge: A Guide for Researchers.* Ottawa, Ontario, Canada: International Development Research Centre.

Haeusler, S.
1995 "Listening to the people: The use of Indigenous knowledge to curb environmental degradation." In D. Stiles, ed., *Social Aspects if Sustainable Dryland Management.* New York: John Wiley & Sons, pp. 179-188.

Haig-Brown, C.
2000 "Some thoughts on protocol in university/community partnership." [Web Page] 2000; Accessed 2002 July 25. Available at: www. oise.utoronto.ca/depts/ sese/csew/nall/res/ 16somethoughts.htm.

Haig-Brown, C. and Archibald, J.
1996 "Transforming First Nations research with respect and power." *International Journal of Qualitative Studies in Education* 9(3): 245-67.

Hanna, M.G.
1999 "A time to choose: 'Us' versus 'them,' or 'all of us together.' *Plains Anthropologist* 44(170): 43-53.

Hedley, M.J.
1986 "Community based research: The dilemma of contract." *The Canadian Journal of Native Studies* 6(1): 91-103.

Hermes, M.
1997 *Research Methods as a Situated Response: Towards a First Nations' Methodology.* Northfield, MN: Carleton College.

Hernandez-Avila, I.
1996 "Mediations of the spirit: Native American religious traditions and the ethics of representation." *American Indian Quarterly* 20(3/4): 329-353.

Hoare, T., M.P. Robinson, and C. Levy
1993 "Participatory action research in native communities: Cultural opportunities and legal implications." *The Canadian Journal of Native Studies* 8(1): 43-68.

Holmes, W., P. Stewart, A. Garrow, I. Anderson, and L. Thorpe
2002 "Researching aboriginal health: Experience from a study of urban young people's health and well-being." *Social Science and Medicine* Apr. 54(8): 1267-79.

Hooley, N.
2000 "Reconciling indigenous and western knowing." Paper given at Australian Association for Research in Education, Sidney, Australia.

Humphrey, K.
2000 *Indigenous Health and 'Western Research.'* Melbourne: VicHealth Koori Health Research and Community.

Huntington, H.P. and E.F. Fernandez-Gimenez
1999 "Indigenous knowledge in the arctic: A review of research and applications." *Indigenous Knowledge and Development Monitor* 7(3): 11-14.

Janke, T.
1997 *Our Culture, Our Future.* Australia: Australian Institute of Aboriginal and Torres Strait Islander Studies.

John, R.
1990 "The uninvited researcher in Indian country: Problems of process and product conducting research among Native Americans." *Mid-American Review of Sociology* 14(1/2): 113-133.

Kahnawake Schools Diabetes Prevention Project
1996 *Kahnawake Schools Code of Research Ethics.* Kahnawake: Kahnawake Schools.

Kavanagh, K., K. Absalom, W. Beil, and L. Schliessmann
1999 "Connecting and becoming culturally competent: A Lakota example." *Advances in Nursing Science* 21(3): 9-31.

Kimberly Aboriginal Health Workers
1992 "The importance of aboriginal research feedback." *Aboriginal and Islander Health Worker Journal* 16(2): 4-6.

Kirkness, V.J. and R. Barnhardt
1991 "First Nations and higher education: The four R's- respect, relevance, reciprocity, responsibility." *Journal of American Indian Education* 30(3): 1-15.

Kone, A., M. Sullivan, K.D. Senturia, N.J. Chrisman, S.J. Ciske, and J.W. Krieger
2000 "Improving collaboration between researchers and communities." *Public Health Reports* 115(2/3): 243-8.

Kurelek, C.
1992 "Anthropological participatory research amongst the Innu of Labrador." *Native Studies Review* 8(2): 75-97.

Laird, S.A.
1999 *Equitable Biodiversity Research Relationships in Practice: Written Agreements Between Communities and Researchers.* Waterbury Centre, VT: World Wildlife Federation.

Lassiter, L.E.
2001 "From 'Reading over the shoulders of Natives' to 'Reading alongside Natives,' literally: Toward a collaborative and reciprocal ethnography." *Journal of Anthropological Research* 57: 137-149.

Lauderdale, P. and A. Oliverio
1995 "Justice, ethics and liberation: the struggle of Andre Gunder Frank." *International Journal of Comparative Sociology* 36: 131-148.

Ledwon, L.
1997 "Native American life stories and 'authorship': legal and ethical issues." *American Indian Quarterly* 21(4): 579-594.

Little, M.
1999 "Research, ethics and conflicts of interest." *Journal of Medical Ethics* 25(3): 259-62.

Lockhart, A. and D. McCaskill
1986 "Toward an integrated, community-based, partnership model of Native development and training: A case study in process." *Canadian Journal of Native Studies* 6(1): 159-172.

Lujan, C.
1989 "Educating the researchers." *American Indian and Alaska Native Mental Health Research* 2(3): 75-76.

Macaulay, A.C., L.E. Commanda, W.L. Freeman, N. Gibson, M.L. McCabe, C.M. Robbins, and P.L. Twohig
1999 "Participatory research maximises community and lay involvement." British Medical Journal 319: 774-778.

Manderson, L., M. Kelaher, G. Williams, and C. Shannon
1998 "The politics of community: negotiating and consultation in research on women's health." *Human Organization* 57(2): 222-229.

Masuzumi, B. and S. Quirk
1993 *A Participatory Research Process for Dene or Métis Communities.* Sombak'e, Denendeh: Dene Tracking.

McCormick, R.M.
1998 "Ethical consideration in First Nations counselling and research." *Canadian Journal of Counselling* 32(4): 284-297.

McNab, D.T.
1986 "Some reflections on the life and hard times of an Indian land claims researcher." *Canadian Journal of Native Studies* 6(1): 129-139.

Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada
1998 Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Canada: Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada.

Miller, P. and S. Rainow
1997 "Commentary: Don't forget the plumber: Research in remote aboriginal communities." *Australian and New Zealand Journal of Public Health* 21(1).

Moewaka Barnes, H.
2000 "Collaboration in community action: A successful partnership between indigenous communities and researchers." *Health Promotion International* 15(1): 17-25.

Mohatt, G.V.
1989 "The community as informant or collaborator?" *American Indian and Alaska Native Mental Health* 2(3): 64-70.

Moore, D.L.
1997 "Rough knowledge and radical understanding: Sacred silence in American Indian literatures." *American Indian Quarterly* 21(4): 633-663.

National Aboriginal Health Organization
2000 *Ethics Guidelines for Aboriginal Communities doing Healing Work.* Ottawa, Ontario: National Aboriginal Health Organization.
2002 *Governance of Research Involving Human Subjects: Research Brief.* Ottawa, Ontario: National Aboriginal Health Organization.

Olubas, B. and L. Greenwell
1999 "Re-membering and taking up an ethics of listening: A response to loss and the maternal in 'The stolen children'." *Australian Humanities Review* July.

O'Neil, J.D., J.M. Kaufert, P. Leyland and W.W. Koolage
1993 "Political considerations in health-related participatory research in Northern Canada." In M. Dyck, and J.B. Waldrum, eds. *Anthropology, Public Policy, and*

Native Peoples in Canada. Montreal: McGill Queen's University Press, pp. 215-232.

O'Neil, J.D., J.R. Reading, and A. Leader
1998 "Changing the relations on surveillance: The development of a discourse of resistance in Aboriginal epidemiology." *Human Organization* 57(2): 230-237.

Paula, Lino
2001 "Ethics: the key to public acceptance of biotechnology?" *Biotechnology and Development Monitor* 47: 22-23.

Piquemal, N.
2001 "Free and informed consent in research involving Native American communities." *American Indian Culture and Research Journal* 25(1): 65-79.

Posey, D.A., G. Dutfield, and K. Plenderleith
1995 "Collaborative research and intellectual property rights." *Biodiversity and Conservation* 4: 892-902.

Posey, D.A. and G. Dutfield
1996 *Beyond Intellectual Property: Toward Traditional Resource Rights for Indigenous Peoples and Local Communities.* Ottawa, Ontario, Canada: International Development Research Centre.

Red Horse, T., T. Johnson, and D. Weiner
1989 "Commentary: Cultural perspectives on research among American Indians." *American Indian Culture and Research Journal* 13(3/4): 267-271.

Royal Commission on Aboriginal People
1993 "Royal Commission on Aboriginal People: Ethical Guidelines for Research." *Northern Health Research Bulletin*: 6-8.

Ryan, R.A. and J.D. Spence
1978 "American Indian mental health research: Local control and cultural sensitivity." *White Cloud Journal* 1: 15-18.

Scott, C.
1996 "Science for the west, myth for the rest?" In L. Nader, ed. Naked Denial: *Anthropological Inquiry into Boundaries, Power, and Knowledge*. New York: Routledge.

Scott, K. and O. Receveur
1995 "Ethics for working with communities of Indigenous Peoples." *Canadian Journal of Physiology and Pharmacology* 73: 751-753.

Scrimgeour, D.
1993 "Ethics are local: engaging cross-cultural variation in the ethics for clinical research." *Social Science and Medicine* 37(7): 957-958.

Sharp, R.R. and M.W. Foster
2002 "Community involvement in the ethical review of genetic research: Lessons from American Indian and Alaska native populations." *Environmental Health Perspectives* 110(2): 145-148.

Sillitoe, P.
1998 "The development of indigenous knowledge: A new applied anthropology." *Current Anthropology* 39(2): 223-252.

Simpson, T. and V. Jackson
1998 "Effective protection for Indigenous cultural knowledge: A challenge for the next millennium." *Indigenous Affairs* 3: 44-56.

Smith, L.
1997 *Decolonizing Methodologies: Research and Indigenous Peoples.* London: Zed Books.

St. Denis, V.
1992 "Community-based participatory research: Aspects of the concept relevant for practice." *Native Studies Review* 8(2): 51-74.

Stager, J.
1994 *Canada and Polar Science, Yellowknife, NWT.* Yellowknife, NWT: Canadian Polar Commission.

Stubben, J.
1997 "Culturally competent substance abuse prevention research among rural Native American communities." *National Institute on Drug Abuse Research Monograph* 168: 459-83.

Thomas, W. and S. Jacobs
1999 "'... and we are still here': From 'berdache' to two-spirit people." *American Indian Culture and Research Journal* 23(2): 91-107.

van Holst Pellekaan, S.
2000 "Genetic research: What does this mean for Indigenous Australian communities?" *Australian Aboriginal Studies* 1/2: 65-75.

Wax, M.L.
1991 "The ethics of research in American Indian communities." *American Indian Quarterly* 15(4): 431-457.

Weaver, H.N.
1997 "The challenges of research in Native American communities: Incorporating principles of cultural competence." *Journal of Social Services Research* 23(2): 1-15.

Weber-Pillwax, C.
1999 "Indigenous research methodology: Exploratory discussion of an elusive subject." *Journal of Educational Thought* 33(1): 31-45.

Weijer, C.
1999 "Protecting communities in research: Philosophical and pragmatic challenges." *Cambridge Quarterly of Healthcare Ethics.* Cambridge, Mass.: Cambridge University Press.

Weijer, C. and E.J. Emanuel
2000 "Protecting communities in biomedical research." *Science* 289: 1142-1144.

Winch, J. and K. Hayward
1999 "'Doing it our way': Can cultural traditions survive in Universities?" *New Doctor* Summer: 25-27.

Wright, R.M.
1988 "Anthropological presuppositions of indigenous advocacy." *Annual Review of Anthropology* 17: 365-90.

Young, T.K.
1995 "Editorial." *Arctic Medical Research* 54: 114-115.