



# INDIGENOUS PEOPLES' HEALTH RESEARCH CENTRE

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## Kwayask itôtamowin: Indigenous Research Ethics

Report of the  
Indigenous Peoples' Health Research Centre  
to the  
Institute of Aboriginal Peoples' Health and the  
Canadian Institutes of Health Research

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## Foreward

The Indigenous Peoples' Health Research Centre, a joint initiative of the University of Saskatchewan, the University of Regina and the First Nations University of Canada, has the pleasure to share its report, *Kwayask itôtamowin: Indigenous Research Ethics*. The report overviews key ethics issues in the research literature with a legal review of emerging issues pertaining to Aboriginal ethics based research, and presents "*Kwayask itôtamowin*" – the words of the Elders on matters of ethics and ethical conduct in research. This report was made possible with support from a grant from the Aboriginal Capacity and Developmental Research Environment (ACADRE) program of the Institute of Population Health and the Canadian Institutes of Health Research.

As part of a series of ACADRE consultations and papers, it is hoped that the review and Elders' dialogues and legal explorations undertaken by the Indigenous Peoples' Health Research Centre will contribute to a wider understanding of research ethics issues as they pertain to Aboriginal peoples and communities.



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Kinanāskomitin Keyteyak ekwa Kāhkiyāw Niwāhkomākānāk

We are living in the time of the parenthesis, the time between eras.  
Those who are willing to handle the ambiguity of this in-between period  
and to anticipate the new era will be a quantum leap ahead of those who  
hold on to the past.

John Naisbitt (1982)  
Megatrends

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**i. Clarification of Terms**

Indigenous Peoples are the tribal peoples in independent countries whose distinctive identity, values, and history distinguishes them from other sections of the national community. Indigenous Peoples are the descendants of the original or pre-colonial inhabitants of a territory or geographical area and despite their legal status, retain some or all of their social, economic, cultural and political institutions.

This review will use the terms “Indigenous”, “Aboriginal”, “Native”, “Indian”, and “First Nations” interchangeably. These terms refer to the first peoples of Canada and, with the exception of “First Nations” which generally refers to Indians who have “status” under the Indian Act, are inclusive of Indians as defined in the Canadian constitution – that is to say, Indian, Inuit, and Metis people.

The term “Western” which is used with regularity throughout our works refers to a mindset, a worldview that is a product of the development of European culture and diffused into other nations like North America. According to Means (1980) “people are not genetically encoded to hold this outlook; they are acculturated to hold it” (cited in Graveline, 1998, p.23). As the “dominant meaning system” Western discourse is the primary expression of that culture (Minnich, 1990). It is the comprehensive repository of the Western experience that wills into being intellectual, political, economic, cultural, and social constructs of Western society and is therefore embedded within all the standing disciplines of the Western academy.

The term “Community” will be used to refer to the system of relationships within Indigenous societies in which the nature of person-hood is identified. Often we use this term to refer to a band or tribal council group. This system of relationships not only includes family, but also extends to comprise the relationships of human, ecological and spiritual origin. Community is a structure of support mechanisms that include the personal responsibility for the collective and reciprocally, the collective concern for individual existence. Cajete (1994) suggests “community is the place where the forming of the heart and face of the individual as one of the people is most fully expressed” (p. 164). It is the primary expression of a natural context and environment where exists the fundamental right of person-hood to be what one is meant to be.

## 1.0 Executive Summary

In the spring of 2004, the Institute of Aboriginal Peoples' Health (IAPH) called for input from the Aboriginal Capacity and Developmental Research Environment (ACADRE) centres in the form of literature reviews and projects that might glean information about ethics from Aboriginal communities. The Indigenous Peoples' Health Research Centre (IPHRC) in Saskatchewan responded to the call and undertook to explore the issue of Aboriginal health research ethics through a three-fold project; a literature review, a legal issues review, and a series of dialogues with the Elders in Saskatchewan.

The literature review summary highlights the findings and recommendations from the recently released *The Ethics of Research with Indigenous Peoples* authored by IPHRC. The legal review is intended to explore potential and emerging legal issues that arise as a result of the assertion of Indigenous ethics and culturally relevant and ethical research practices and procedures at the national, regional, academic, and local community levels. We engaged in this project in order to ensure that the voice of our communities informs the revision process and, ultimately, to ensure that Aboriginal health research, as it unfolds in the future, does not perpetuate harm, suspicion, and further mistrust for our communities. Rather, we seek to support the development of paradigms that intrinsically protects the Indigenous knowledge and the aspirations of our communities. The Elders' dialogues summaries presented in narrative form are intended to represent the voice of the Elders in Saskatchewan on issues pertaining to community focused research and the ethics thereof.

The Indigenous concept of community and its epistemological underpinnings represent spaces from which it is possible to re-theorize the universal and legitimize models for ethical social relationships that are inclusive and therefore potentially benefit all of humanity. New frontiers of knowledge that have been ignored and suppressed through the 'time-lagged colonial moment' (Bhabha, 1994) are observable from alternate spaces of knowledge represented by the Indigenous community. These are spaces constituted by discourses in Indigenous languages, worldviews, and community aspirations for an ethical order in society – a knowing that contrasts with Western notions of the universal. Reclaiming voice and reclaiming vision through community models become necessary processes for Indigenous Peoples to re-establish a sense of true identity and to be able to assert the Indigenous mind and discourse in ways that bring honor to the community.

The Elders who participated in the dialogues stressed that the community knowledge is an Indigenous right. The sacred knowledge held by individuals and commonly by the community is the foundation of truth for the people. It is the basis of the peoples' existence and reality. The gifts of knowledge that the people possess are special in this way because they have been obtained through a special covenant the people have with the Creator and Mother Earth. Special gifts of knowledge held by people in the communities are often obtained through traditional and spiritual processes. The Elders said that sacred knowledge is Creator inspired and is to be cherished as a gift given to the people for their own use. This knowledge, commonly tied to the practices of sacred performance but not limited to that domain, is entrusted to the people to maintain and protect as a responsibility. This is based on the assertion that everything that has been given to the people in a sacred manner, through spiritual observances is to be kept in its sacred state. In this respect, requesting the approval and assistance of the spirits is done first in order for something to be done

with the knowledge. That is the truth of the people. The Elders said clearly that communities have a responsibility for the maintenance and integrity of the local knowledge. They said that there was a culturally appropriate way that the knowledge is viewed and handled.

Within the knowledge system, Elders have different roles, and different responsibilities and teachings for the purpose of maintaining that order. There are processes in place by which the truth of the community and its vitality are maintained. Maintaining values of the people is important for the protection of the knowledge. Another way of maintaining and protecting this knowledge is to keep it within the context of the communities' culture and for the community people to work together in its maintenance and protection. One Elder indicated that people cannot disclose any of their special gifts because they are of a sacred nature.

The notion of a knowledge tradition, complete with its luggage of beliefs, context, and processes imposing into another knowledge domain, ad hoc, elicits something improper. It speaks of unethical practice and it provides additional dimension to the notion of 'honor of the crown.' The voice from the Elders, and indeed from supreme court rulings, remind us of the need for cross-cultural dialogue for the objective of ethically engaging different knowledge systems. According to Bohm (1996), dialogue enables inquiry into processes that can fragment and interfere with real communication between individuals, nations, and even different parts of the same organization. Dialogue is concerned with providing a space for exploring the field of thought and attention is given to understanding how thought functions in governing our cross-cultural behaviors. It is a way of observing, collectively, how hidden values and intentions can control our behavior, and how unnoticed cultural differences can clash without our realizing what is occurring. Cross cultural research has been problematic because of this neglect for the unseen, unstated influential undercurrent of hidden values and intentions.

The Elders remind us to have 'conversations' as equals. The act of dialogue is the act of resolving the confrontation and is itself an ethical act. This will entail the examination of structures and systems in attempts to remove all vestiges of colonial and imperial forms of knowledge production and to instill a respect and understanding of different and multiple readings, and different jurisdictions of the world. It will be in the ethical space where all assumptions, biases, and misrepresentations about the 'other' are brought to bear in the interest of identifying ethical/moral principles in cross cultural interaction.

From the perspective of our understanding of ethics, based upon the literature review, an exploration of liability issues, combined with the findings of the series of dialogues with Elders and traditional knowledge keepers, we make the following recommendations with respect to the ethics of research with Indigenous peoples:

- To protect the heritage of a sacred body of knowledge, Indigenous Peoples, and in particular the Elders and knowledge keepers of each community, must be informed and exercise control over all research that relates to heritage within their territories.
- The Granting Agencies as well as academic and other research institutions should explicitly recognize the rights and privileges of alternate knowledge systems represented by Indigenous Peoples. This recognition should include the support and development of

educational, research and training centres that are controlled by indigenous communities, and strengthen these communities' capacity to document, protect, teach and apply all aspects of their heritage.

- Governments, research institutions, and Research Ethics Boards should discourage institutional based research regarding any element of Indigenous Peoples heritage without the explicit approval and guidance of Indigenous authorities, Indigenous Elders and knowledge keepers.
- In the event of a dispute over the custody or use of any element of an Indigenous Peoples' heritage, judicial and administrative bodies should be guided by the advise of Indigenous Elders who are recognized by the indigenous communities or peoples concerned in having specific knowledge of traditional laws.
- Researchers must not publish information regarding any information or knowledge obtained from Indigenous peoples or the results of research conducted on flora, fauna, microbes or materials discovered through the assistance of Indigenous Peoples.
- The jurisdiction of Indigenous Peoples over their culture, heritage, knowledge, and political and intellectual domains must be explicitly recognized in the Tri-Council Policy Statement and in review documents and proposals currently being developed.
- In recognition of Indigenous jurisdiction, research agreements need to be negotiated and formalized with authorities of various Indigenous jurisdictions before any research is conducted with their people. Concepts of OCAP; ownership, control, access, and possession of all data and information obtained from research involving Indigenous Peoples, must become normative standards. Emerging critical issues include:
  - Negotiations on “benefit sharing” and “benefit sharing agreements” in Genetic research must not take place in advance of genuine Indigenous community consultation and consent.
  - Genetic and biological research must cease until Indigenous authorities have articulated specific direction on these issues from Elders, leaders, and communities.
- Indigenous community empowerment and benefits must become central features of any research entertained and conducted with respect to Indigenous Peoples. Professional associations of scientists, engineers and scholars, in collaboration with Indigenous Peoples, should sponsor seminars and disseminate publications to promote ethical conduct in conformity with these guidelines and develop processes and structures to discipline members who act in contravention.
- Understanding Indigenous worldviews, social structures and systems, and the role of education and pedagogical forms in the process of knowledge and cultural transmission, is a vital necessity in coming to terms with research involving Indigenous Peoples. Education and knowledge translation projects in these respects must be supported with appropriate funding and resources.

- Steps must be taken to immediately implement policy that will ameliorate inherent conflicts between Research Ethics Board policies and Indigenous ethical requirements, the primary example being the barriers to meaningful negotiation of consent and research parameters on the part of community participants prior to the receipt of formal approval from institutional Research Ethics Boards.
- Further conceptual development of the ethical space will require guideline principles put into effect by the three granting agencies that cement practices of dialogue, negotiation, and research agreements with Indigenous authorities in any research involving Indigenous Peoples.
- Ongoing efforts by scholars and political groups to formulate the parameters of national copyright laws and the protection of Indigenous Peoples' intellectual and cultural property rights must take extreme urgency. Protection and recognition of Indigenous peoples' intellectual and cultural property rights by researchers and institutions must be part and parcel of any funding received from the three granting agencies.

## 2.0 Introduction

In the early part of 2004, the Institute of Aboriginal Peoples' Health under the auspices of the Canadian Institutes of Health Research put forth a request for proposals to the Aboriginal Capacity and Developmental Research Environment (ACADRE) institutes on the subject of Ethics and research with Aboriginal populations. The IPHRC submitted a proposal to build upon a recently completed literature review on the Ethics of Research with Indigenous Peoples (IPHRC, 2004) by conducting further literary explorations into one of the recommendations arising from that report; namely, an examination of the legal implications and issues of jurisdiction and intellectual property that might arise in the future as the result of research ethics processes based upon an Indigenous ethical framework. In addition, the IPHRC proposed to bring together Elders from across the province of Saskatchewan for dialogues towards an understanding of ethics and ethical conduct as it pertains to Aboriginal Health Research.

The IPHRC team is well versed in research practices and our staff members are representative of both Aboriginal and non-Aboriginal academic and health research communities. The IPHRC is an organization that is fully engaged in the Aboriginal health research enterprise and the team is committed to the exploration and implementation of the ethics in research that are aligned with the interests, rights, and protections of Aboriginal peoples. We are ideally situated to speak to unfolding methodological and ethical issues as the result of ongoing and reciprocal dialogues and relationships with Indigenous communities in the province. In research with Aboriginal peoples, the notion of relationship is a foundational one; research cannot occur without trusting relationship. The IPHRC has built upon existing personal and professional relationships and has been dedicated to building research networks. We, therefore, undertake the surveying of our communities with great caution and respect and strive to keep the interests of our communities at the top of our priorities. The IPHRC is positioned to make vital, respectful links between mainstream research bodies and Aboriginal communities, and philosophically oriented to comprehend, articulate, and translate traditional concepts and constructions of ethics that currently exist within the purview of the Elders and traditional knowledge keepers.

There exists a growing body of perceptive writings that provides new avenues of thought in decolonizing the research process. Indigenous scholars, with the professional support of non-Indigenous critical analysts from many Western institutions, contribute a much-needed injection of academic guidance in these matters of research. This summary of a recent critical reading of the literature – *The Ethics of Research with Indigenous Peoples (2004)* -is intended to highlight the body of dissension expressed by various critics to the nature and ethics of research involving Indigenous Peoples. In the first section of this report, we summarize those concerns to reveal the broad scope of critique that stands as a testimony to the ethical breaches in the history of research involving Indigenous Peoples in North America and many parts of the globe. Further reading identifies crucial aspects in the research enterprise that, in their present configuration, have a cumulative bearing on the ethical issues and concerns expressed about research involving Indigenous Peoples, and reveal legal implications that may emerge concurrent with an order of research founded upon Indigenous ethics.

With these issues in mind, we assert Indigenous perspectives on research and reclaim a voice that contributes to the dismantling of an old order of research practice. The shift to new

paradigms of research is 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, Sinclair & Jeffery, 2004). We anticipate that our work from the research margins will help usher in new research relationships that are modeled on emancipation and a human vision of transformation.

There are several elements to this report. The Elders' dialogues summaries are intended to represent the voice of the Elders in Saskatchewan, with little or no interpretation or alteration of their words and thoughts only in the sense that they are provided in narrative and thematic form. It is our belief that the thoughts of Elders should stand as they were intended. However, we do offer a brief summary of key issues. The literature review summary is intended to highlight IPHRC's recent literature review findings and recommendations in this forum and to reiterate and highlight some of the more salient issues of the ethics revision discourse. The legal review is intended to explore potential and emerging legal issues that arise as a result of the assertion of Indigenous ethics and culturally relevant ethical research practices and procedures at the national, regional, academic, and local community levels. This report concludes with our recommendations with respect to research ethics in Indigenous research generally, and Aboriginal health, specifically.

### **3.0 Theoretical Perspective**

The IPHRC team uses, as a guiding theoretical framework in the exploration of Aboriginal health research ethics, the concept of the 'ethical space' (Poole, 1972 as cited in Ermine, 2000) that exists at the meeting point between the dominant western research paradigm and the emerging Aboriginal epistemological discourse. According to Ermine, this confrontation of worldviews sets up the conditions by which a protracted engagement of dialogue is necessary for the pursuit of ethical interaction. The current order of research, established from western hegemonic modes of thought requires the urgent advancement of a new research order for the expression of ethical principles in studies that cross cultural borders and specifically involve Indigenous Peoples. This shift in consciousness will not and cannot be manifested through the lenses of Western thought alone. It requires models of new knowledge and pedagogy from different worldviews, in a cooperative spirit between Western institutions and Indigenous Peoples in manner that brings honor to all. We contend that the concept of ethical space is particularly important at this time in history because our research, particularly the Elder dialogues contained herein, indicate the rift between knowledge systems and the lack of understanding on the part of the 'west' with respect to Indigenous lifeways. The ethical space represents one element of the unknown terrain of the "seventh movement" - the future of qualitative research - as described by Denzin and Lincoln (2003) and how the unknown future will be configured is essential for respectful and collaborative research relationships to unfold and exist in the future. We assert that the presentation of community based dialogues from Indigenous Elders represents a manifestation of Indigenous thought and knowledge that must be respected and honored in its own right.

This report is the culmination of an intention of the IPHRC to confer with traditional knowledge keepers on all aspects of our emerging research program. The IPHRC initiated dialogue in the area of Aboriginal community based health research ethics and education initiatives in early March 2004. We gathered together regional Aboriginal health organizations and research centre representatives to discuss the issues of research ethics that are emerging as community based

research projects and community-academic research partnerships develop and increase in numbers in our province. The purpose of this initial consultation was to formulate a general picture of the pressing ethical questions and concerns that are circulating in response to the increase in activity in Aboriginal health research. This initial dialogue provided an excellent foundation for further ethics-focused activities. In the Spring of 2004, the IPHRC submitted a successful literature review proposal to the SSHRC to conduct a review of research ethics with Indigenous Peoples. The current report builds upon the literature review and comprises our most recent ethics based activities. In order to complete this particular piece, we defined a set of guiding principles for the work.

### **Objectives of the project**

1. To learn about Aboriginal ethics from Elders and traditional knowledge keepers;
2. To explore traditional constructions, understandings and definitions of ethics in knowledge production;
3. To explore traditional understandings of consent and relate these to contemporary notions of informed consent;
4. To articulate the philosophical and theoretical premises for ethical research conduct and notions of consent through Elder dialogues;
5. To translate this knowledge into a form that can be applied to research practices;
6. To contribute sound Indigenous community-based wisdom to the national Aboriginal research ethics project.

### **4.0 Methodology**

In December 2004 and January 2005, the IPHRC team met with Elders representing the Nēhiyaw, Nakawe, and Dakota nations. In total, the IPHRC brought together 34 Elders from across the province for the dialogues on community health, research and knowledge protocol. The result of these dialogues produced a working paper that starts to articulate the language of knowledge ethics from the First Nations community and specifically from the Elder perspective. The Elders' dialogues focused on two questions related to the proposal:

1. What are the Elders' views as to knowledge and specifically about ethics of research that crosses cultural borders.
2. What are the ethical guidelines required for the proposed research process?

To explore these issues, a First Nations traditional learning tool—an Elders' forum—was identified as the most appropriate methodology. This method was chosen because of a number of important benefits. First, by following traditional protocols, the Elders' forum brought together knowledgeable Elders to an appropriate setting in which they could share their information amongst themselves as well as with the IPHRC. The Elders' forum also provided a foundation for future initiatives such as focused case studies and/or further development of the research protocols as determined by the interests of the Elders and IPHRC.

The physical format of the Elders' forum incorporated a central table around which all the Elders gathered for discussions. The forum was open for Elders to talk freely in their First Nations

language and the process of the roundtable dialogues enabled the Elders to support each other in recounting and articulating knowledge tradition in particular as it relates to cross cultural protocol. According to protocols commonly followed in First Nations communities, the Elders' forum was based on a spiritual foundation of prayers and involved implementing the necessary protocols for the transfer of knowledge. All costs for the Elder delegates—including honoraria, travel costs, and meals—were covered by funds received from IAPH and the CIHR.

The academic writers who are linked to the Elders' forum are perceived as *Oskapiwis*—a Cree word that translates loosely as “servant”—to the First Nations knowledge system. They are expected to perform their skills and duties under the support and direction of that system. In this particular instance the work of the *Oskapiwis* is to facilitate the dialogue between First Nations and western worldviews. In this respect, the facilitators, academics, and writers associated with the Elders' forum need to work from a position that is reflective and respectful of both systems. Our research team consisted of Willie Ermine, the IPHRC Ethicist; Raven Sinclair, the IPHRC Community Research Facilitator for the central Saskatchewan region, and our research assistant, Delores Young. We also utilized a community based research assistant, Vern Harper, for various activities including protocol liaison, traditional food supplier, and translator.

The Elders dialogues were not audio recorded because Elders often see such practices as intrusive to the notion of dialogue; and counterproductive to traditional oral based pedagogy. The two Cree speakers on the team took notes and transcribed the dialogues into English for this report. The words of the Elders pertaining to the issue at hand are contained herein intact, although we have included a brief commentary of key issues after the dialogue text. Other than the translation, we chose to honor their thoughts and words as they were spoken and, hence, those ideas are recorded in this report as they were translated, without interpretation or analysis. They have been recorded under thematic categories for ease in reading. The discourse of the Elders from the three dialogues is interwoven into this text.

## **5.0 Isi wâpahtahkik : How They See it**

It is important that the difference between the First Nations and western knowledge systems be clearly defined in the beginning of this discussion. Cajete (2000) cautions that “Western and Native science traditions are very different in terms of the ways in which people come to know, the ways in which knowledge or understanding is shared, how knowledge is transferred from one generation to another, and how knowledge is handled legally, economically, and spiritually.” As much as western knowledge gathering is guided by principles of knowledge production and reproduction, the First Nations knowledge tradition similarly operates under a set of guidelines or protocols. The Elders' dialogues are presumed to operate under the protocols of the participant First Nations. The development of the forum is guided by principles of ownership, control, access, and protection<sup>1</sup> of information where intellectual property rights are weighted to the advantage of the Elders. Philosophically speaking, the Elders' dialogues, as a methodology, does not need validation from any other knowledge institution nor is it presumed that the western

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<sup>1</sup> For a discussion of these principles as they apply to research see Brian Schnarch, “Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities,” *Journal of Aboriginal Health*, Vol. 1, No. 1 (January 2004) p. 80-95.

conventions of knowledge production apply in the First Nations' cultural context. While it may overlap to some degree with qualitative research methods in the social sciences (such as oral history research and participatory action research) it takes its ultimate authority and validation from First Nations cultural traditions and protocols for knowledge production and transfer.

For the Elders, the gathering format is a traditional learning process that is a central feature of First Nations knowledge systems. It is important for the centre of control to remain with First Nations communities. As such, it is helpful in bringing about the re-establishment of a First Nations institution. The Elders are scholars in their own right within the First Nations knowledge system. A primary goal of the Elders dialogues is to provide supportive conditions for that knowledge system to function and flourish. These conditions include spiritual and cultural observances and the use of First languages. As Roberto Unger (1984) suggests, if an environment allows people to move within it to discover everything about the world freely, it is a natural setting. If the environment does not allow such movement, it is artificial.

Included here is the disclaimer that the source of any Indigenous understanding that is written about here is from the Indigenous body of knowledge embedded in the Elders that we were privileged to dialogue with. This knowledge we cannot claim as our own, but we recognize that we are part of the participatory mind and social product of that knowledge. We also recognize that there are multiple and distinct nations of First peoples and therefore any references to Indigenous knowledge are founded to the commonality of principles that guide Indigenous peoples worldviews. This clarification will highlight our responsibility to give recognition to this multiplicity and also the protection of Indigenous knowledge as a sacred trust functioning outside of and beyond the perimeters of individualized western scholarship. The following section articulates the thoughts of the Elders that were a part of the Elder Dialogues and their discourse on research ethics is interwoven as narrative in the following text.

## **5.1 The Context of Traditional Knowledge**

The Elders had many memories of the traditional lifestyle they grew up in. Their memories of the past included a life style that was largely determined by self-sufficiency. The people had power in traditional times, in terms of health and self-sufficiency, because they used their own resources for their livelihoods. The Elders indicated that the traditional lifestyle was a healthy way of life and people were largely content. The traditional lifestyle had important qualities for the health of the people and the diet of the people was very important. The traditional lifestyle was closely linked with the natural world and the connection people had with their environment and the pursuit of ceremony gave the people a certain kind of power. The Elders said that the traditional foods, like moose, ducks, rabbits, and berries that the people ate had medicinal qualities. The Elders did not see any negative effects on them either in the past or in the present from that kind of life. In that traditional life, sacred land was protected and kept pure. Presently, traditional foods are still important for a healthy life and the Elders spoke strongly against the contemporary diets influenced by the mainstream urbanized society. They spoke of the quality of the variety of traditional foods that were healthier than the contemporary type of food purchased in stores. The diet changes that resulted from the purchase of contemporary foods had certain impacts on the health of people.

The Elders said that knowledge and values had significance in traditional life. This traditional life was hard compared to the contemporary lifestyle, but it was also very rewarding because of the values that were developed and held. The life they lived helped them attain certain values that were important to have as Indigenous people. These values in turn maintained the integrity of the people. Family values were considered important because it was in this familial context that parents could relate, talk to and teach their children the idiosyncrasies of culture and its protocols. Children were taught the value of a good home life and encouraged to cherish the home as a teaching venue. The family focus was also the ideal context where the value of Elders was also instilled. Children were taught that sicknesses arise by not listening to what Elders said. They were shown that people needed clear and clean minds to stay healthy. Values like truth and to cherish life were taught and enforced on children in the home. These were the practical ways and beliefs that kept their communities functioning. These are the reminders that the Elders stressed.

The old people of the community had a vital role in that traditional life. The old people were responsible for passing on the knowledge and the teachings that went with the knowledge. The old people also provided the counseling to younger people. There was mutual reciprocity where younger couples kept the old people and in turn received knowledge from the old people. A consideration of the age groups in the stages of life contributed to a model of knowledge transmission in the communities. As an example, the young were linked with the old people so that conditions are created where knowledge can be passed on. The traditional system of knowledge connected knowledge holders with knowledge learners. Relationship was also a prime factor in how knowledge would be transmitted in the community. Their educational model included talking with young children about values and knowledge at an early age. The old people knew that young children learn everything by the age of six and that this was a critical period of development. The Elders said that what a child is told at an early age is held in memory and remembered in later life.

## **5.2 Children / Youth**

The Elders had a deep concern for the youth from their communities. Their concern is about the future. They wonder how empowered the future generations will be and how cultural continuity will be maintained. Youth are integral to the notion that community culture will have continuity. The timely passing down of knowledge to the youth is important to the Elders in order for the youth to be strong and capable of making their own decisions. The concerns include thoughts about contemporary influences. The Elders have a perception that mainstream influences are taking over the minds of the children from the communities to the degree that the youth now have a different attitude towards culture and knowledge. One of the effects of this system of education is that it has created disconnection between the youth and the Elders of the community. They indicate that the traditional culture of the communities is not being transmitted because of this disconnect. The Elders see different values being exhibited by the youth and that the education system is different from what they experienced and observed in the past under the traditional lifestyles. The Elders are worried that the effects of mainstream education are causing their youth to be ashamed of their own culture with the youth consequently not believing in its truths.

The Elders stressed that the youth have to learn the knowledge from the community Elders. The transmission of knowledge is done in context and can *only* be done in context. In the

contemporary situation, these contexts are often recreated in cultural camps. The role of the Elders and their contributions is part of the context of community or collective knowledge. There has to be a recognition that the accumulated knowledge of the people is often deeply embedded in the old people. One Elder said that listening to the elders of the past was like looking at a picture (talking about geography for example). The Elders said that the chain of responsibility is broken in our communities. People are overstepping boundaries and others are not doing what needs to be done to promote culture. They recognize that knowledge is deeply embedded in 'old' people that are not commonly found outside of their own community.

The Elders said that communities must always keep the children in mind by teaching them to maintain the traditional knowledge system. Part of this process involves stressing to youth the importance of language and its use in maintaining the knowledge system. However, the youth are not listening to teachings because they do not have the first language. The language shift hampers understanding across generations in many communities. The Elders wonder how people can work together to promote life and one of the important tasks now is to promote language because without it the people are losing the culture. The Elders said that knowledge is embedded in the first language. They said that parents have to persevere in teaching the language to the youth in the face of challenging and uncertain times. One Elder indicated that the culture and language of the communities is waiting for the people, and in particular the youth, to return. The Elders also recognize that the youth are immersed in mainstream education. The question is how do the Elders share stories and knowledge with the youth and others in a contemporary context. The Elders said that the children need Indigenous knowledge for their future survival.

The Elders recognize that sharing the knowledge widely with the youth is also a way of protecting the knowledge. Sharing the knowledge so that it is held by our youth is a way of ensuring that those understandings will continue. The Elders indicated that the youth have to go back to the culture for the sake of healthy communities. The youth need to be reminded that there is value in traditional knowledge and that what they learn in the modern education system is not all there is to learn about maintaining healthy lives. The Elders stressed that the counseling of youth must take place in order for the youth to remember what is important for the culture. This concern extends to the youth residing in communities and those that live in the cities. The Elders also said that the counseling that takes place presently would have a positive impact in the youth's future. One of the Elders indicated that the traditional way of counseling is done at the dinner table while the youth are eating. The Elders say that everything that is done is for the sake of the youth and their future. The Elders expressed some measure of conflict over the promotion of culture to the youth and to protect the knowledge from exploitation from outside interests.

### **5.3 Sacred Knowledge**

The Elders said that there is sacred First Nations knowledge. The Elders suggest that the knowledge has to be grounded to the self, much like spirituality, which is a personal commitment of the individual to the Creative force. So knowledge that is grounded to self, used for spiritual purposes is considered sacred knowledge to the people who hold it. As one Elder said, this sacredness of particular knowledge becomes so because it is often a one on one covenant with the Creative Force.

The Elders relayed the importance of maintaining sacredness in life. The sacred knowledge held by individuals in commonly by the community is the foundation of truth for the people. It is the basis of the peoples' existence and reality. The gifts of knowledge that the people possess are special in this way because they have been obtained through a special covenant the people have with the Creator and Mother Earth. The people in the communities are blessed with special gifts of knowledge that are often obtained through traditional processes. The Elders said that sacred knowledge is Creator inspired and is to be cherished as a gift given to the people for their own use. This knowledge, commonly tied to the practices of sacred performance but not limited to them, is entrusted to the people to maintain and protect as a responsibility. This is based on the assertion that everything that has been given to the people in a sacred manner is to be regarded and kept in its sacred state. In this respect, requesting the approval and assistance of the spirits is done first in order for something to be done with the knowledge. That is the truth of the people.

The Elders said that the because the knowledge of the people has been obtained in sacred ways it is primarily used for community health and well-being. It is also the basis for the reality or the true energy that the people resort to for continued health and grounding. The Elders said that within the traditional First Nations context, the sacred knowledge is effective. Their standard of living included the belief that spiritual beings looked after their lives and it was important to maintain those connections for a healthy life. As one Elder said, "when we are in a negative condition of sorts, we can turn to our knowledge." That is to say the knowledge in all its various forms including healing concepts, seen as process and in real time, is the living foundation and the reality that sustains and keeps people in stability and vitality. The real, true energy that the knowledge manifests is what keeps the people grounded in who they are and what purpose they have in life. The power of sacred knowledge, through ceremonies, keeps people and communities together. In this way, the people are to cherish what is God-given and to keep in trust the sacred realm of the people.

The context in which First Nations knowledge is embedded and has the deepest meaning is a very important consideration. The Elders advise that people go back to the teachings and to do it in a way that respects the context of the knowledge. The power of these gifts of knowledge lies in the hands of the Elders, the knowledge holders, and collectively by the community people. It is a living knowledge. It is the spiritual component of life that is termed as *Pimâtisowin* in Cree. This sacredness, as a covenant, is the basis of what is termed Indigenous knowledge. Sacred action done in the spiritual realm has implications in the physical world. As an example, being involved in ceremony creates a pride and feelings of connectedness to the people and culture. The importance of this involvement is the sharing and being within the collective energy of relatives and one's own people. Sacredness is also manifested in the mornings when all life forms are acknowledged from insects to grass, trees, flowers – all life. The Elders said that ethics is about respect, respect for the whole circle of life. These are values about humanity and these First Nations values are common all over. In the First Nations communities, things not talked about are also respected. There is respect for that which is not talked about, which is often the intimate and sacred knowledge of people's connections with the sacred. People's silence on these matters is respected. The Elders said that these things are in the spiritual realm to promote peaceful life.

On matters concerning knowledge, the Elders stressed that the community possesses and controls local esoteric knowledge. Within the knowledge system, Elders have different roles,

different teachings for the purpose of maintaining that order. There are processes in place by which the truth of the community and its vitality are maintained. The Elders said clearly that communities have a responsibility for the maintenance and integrity of the local knowledge. They said that there was a culturally appropriate way that the knowledge is viewed and handled. The Elders said that there are shifts happening now to the culture. There are even changes happening with how ceremonies are done. The Elders said that the knowledge has to be learned. People have to learn what true knowledge is first before they can know. Elders said that before encountering ceremony or sacred knowledge, one must know the knowledge first before doing or practicing it. People must not jump in without knowing the knowledge first. They also said to approach knowledge with an open mind and to observe.

The Elders said that knowledge is an Indigenous right and therefore this knowledge must be protected. People have to watch their words and actions because of the sacred nature of the knowledge. Maintaining values of the people is important for the protection of the knowledge. Another way of maintaining and protecting this knowledge is to keep it within the context of the communities' culture and for the community people to work together in its maintenance and protection. One Elder indicated that people cannot disclose any of their special gifts because they are of a sacred nature. Another way of protection is for the people to be wary of how they pass on knowledge and to be careful how it is treated. One Elder indicate that it is important that the spiritual leaders maintain their sacred ways and not to be influenced by mainstream values.

#### **5.4 Protocols**

Protocols are the practices by which knowledge is handled. Following the appropriate protocol is an important and crucial process, particularly in the handling of sacred knowledge. The Elders said that people have to be aware of what protocol means in the context of the community in which the knowledge is embedded. The sacredness of the knowledge also requires an understanding of what sacredness means. Therefore, according to the Elders, being aware of protocol, understanding what it means, and its appropriate practice in matters of knowledge is crucially important in the handling of community knowledge. Using protocol, as determined by the community, and specifically by the knowledge holders, serves as ethical practice and the sacred approval to learn and practice the particular knowledge. Without the appropriate protocol, knowledge is not valid and powerless. Without knowledge of the appropriate protocol and without the grounding to knowledge itself, there is a misuse of our First Nations processes, like the use of natural medicines without approval that results in the medicines losing power.

The responsibility for knowledge is shared with an approved learner through the process of protocol. The following of protocol provides the appropriate spiritual forum and approval for the exchange of knowledge from Elder to learner. Because protocol is important, it has to be followed in the proper way within context. For example, particular relationships require certain protocols of behavior with one another. These relationship protocols determined who could talk and who could teach. Within the community system of relationships, these protocols of behavior have to be followed.

The Elders said that this knowledge cannot be released to the general public or to just any individual on an ad hoc basis and without appropriate compensation or commitment. Learning the

knowledge and following the protocol is a part of the knowledge. The Elders said it is important to be aware of what sacredness and protocol mean because it relates to understanding the purity of giving knowledge and for that knowledge to be valid.

## **5.5 Research Process**

The Elders offered guidance in terms of how to structure the research process so that the knowledge obtained is valid according to community standards. They said that the only valid structure of the research process that is acceptable is that research be community focused and locally controlled. The Elders mentioned ownership, control, access, and possession in these deliberations. These issues had to be addressed to make the research valid according to the standards of the community as required in protocol. The Elders also mentioned partnership as valid criteria for any research to be done in their communities. Addressing these issues in the research process would ensure a proper mechanism that produces benefits for the community. The Elders said that the only valid way that research can be done in communities is through partnerships, community ownership of research, and with a community focus and objectives. The Elders said that ownership of knowledge has to be recognized in some form because this knowledge is often the spirit voice of whole families. The Elders said that families should be given tools to protect their knowledge and the means of sharing their knowledge as a way to protection. They said that sharing (teaching) the knowledge is also a way of protecting it because more people will perpetuate its value. The Elders recognize that a fine line exists between the intent to promote the knowledge culture and having it exploited or appropriated by the mainstream.

## **5.6 Concerns about Research**

The Elders said that they had walked the path of research before but the awareness of the research process itself is new. The Elders said that research has always been done on the people and are therefore wary of research that is directed from the mainstream. The Elders voiced various concerns about how First Nations people are portrayed in the mainstream. The information about Indigenous existence that goes out to the mainstream is often superficial and only scrapes the surface of who the First Nations are and what knowledge they possess. The Elders hold the view that the mainstream still needs to be educated about Indigenous reality before sharing deeper knowledge with them. They recognize that there is a fine line that exists between awareness building and disclosure of sacred knowledge and having it appropriated or exploited by the mainstream. When Elders pass on information for awareness, it is not for creating ‘experts’ and medicine people. They said that allowing participation in First Nations ceremony like the sweat-lodge for example is an awareness building exercise and not for giving of the knowledge. People can participate but they must realize they are not given the control of that process.

There is also the tension between western science and Indigenous knowing. They ask that people consider knowledge in western academia and how that interfaces with the knowledge in the First Nations context. The Elders stated that academia has its own rules that are appropriate for knowledge production within its society which are different from First Nation guidelines and protocols. Western academia tries to apply its concepts to Indigenous peoples because it tries to own all the processes of education and knowledge. However, the Elders said that an exchange of knowledge between these two worldviews requires, at the least, open-mindedness about what

exists in the other culture. The Elders said that academics “don’t know what they don’t know.” They state that academia and in particular, the non-Indigenous researchers, are not fully aware of Indigenous ‘ways of knowing’ because these have no basis in western science and western knowledge. Very often information and knowledge in academia is made invalid by the ‘not knowing’ of the academic to appropriately process First Nations information. The Elders said that this fundamental schism prevents mutual understanding because the power of our people lies in the abilities beyond what is understandable through western scientific processes. There is an additional concern about why academia would want to know about the traditional ways of Indigenous knowledge. In the interim, one Elder asked the rhetorical question as to “what would be the benefits to us if we disclosed our sacred knowledge?”

The Elders are also concerned with the pervasiveness of the English language to document knowledge. The Elders recognize the value of knowing and using another language. However, the use of the English language to document Indigenous knowledge has its drawbacks. Indigenous knowledge is embedded in an oral tradition and the concern is that spoken words are at times turned into written knowledge. This can be problematic because translation of Indigenous language into English loses much of the inherent meaning.

The Elders said that in the past knowledge was not dealt through a writing system. In terms of documenting and writing of knowledge, the Elders said that there is an intrusion that happens when certain knowledge is written down. There is an intrusion by writing, that writing is like a sacrilege because it intrudes into a sacred process and writing would destroy that peoples’ connection with the sacred. The Elders said that the act of writing kills spiritual information. This kind of knowledge is internalized, not written. The Elders cautioned to be careful that technology and education are not used in a way that negates or nullifies sacred knowledge. Knowledge comes in the act of processing the information. Words are spoken from the heart and put into memory. As one Elder said, “knowledge is experience; the experience is knowledge.”

The Elders gave examples of what is not ethical. For example they said that ceremonies are sacred to the people who are involved with them and that going through the ceremony is a sacred act for them. Therefore, the Elders said, showing the sacred through the media, like filming of sweat-lodges, is unethical. Another example given by the Elders is the cloning that attempts to recreate the human is wrong and unethical in the Elders way of thinking. The Elders pointed to what scientists do with information. Much of what science does is mystified and hidden with the expectation for the masses to place trust on the scientists. This mystification and misplaced trust is unethical. For example, the Elders also wanted to know what medical establishment does with aborted fetuses. The Elders said that abortion affects the notion that life starts at conception. Conversely, the Elders also gave examples of what is ethical. They gave the example of the midwifery process that was in place in traditional times. The midwife would talk to the baby by telling it what to do and what to be. This chatter with the newborn is an example of ethical conduct in traditional times. This process also included teaching the mother what to do and what behavior to exhibit.

## 5.7 What to Research

The Elders provided opinions as to what is acceptable research that can be done in communities. They understood the idea of recording or documenting information and knowledge before the Elders pass away and gave voice to what can be researched. They said that the primary objective of any research is that it has to benefit the communities. They offered up suggestions as to what types of research might be considered beneficial. They said to research that that would promote our ideas, our ideals, and our professional development. What is researched should enhance the lives of community people or how to better the life of our people through the benefits of research. The work done through research should encourage professional human development. The Elders said that research has to be legalized and communities own the research process and awareness – in the context of the communities involved. The gauge for success in any research is that it has to benefit the community. Local research enhances seeing and placing a problem where it resides. In this respect research that enhances the retention of culture, languages, and other community treasures is required.

Creating a safe environment for research to be carried out is one of the priorities of the Elders. Sensitive issues and sacred information that cannot be disclosed would warrant crucial attention and for the careful interpretation and translation of any information accessed in the community. Should that security be assured, the Elders saw the value of research as a process that would enhance the community understanding itself. Research can be used as a catalyst for the community to examine itself and to understand its internal cultural processes more clearly. The Elders said that community people needed to see the strength in their own ways of culture. Communities required the time to do their own internal research, to examine the similarities in First Nation cultures, for example, without jeopardizing the integrity of the knowledge system. The research process can contribute to communities nurturing their own spirit. For the Elders, valid research is any work that is done internally to enhance cultural pride and understanding. The research process had to be internally controlled and owned because the communities understand their own internal processes. The Elders said that communities need to assert their heritage to protect the knowledge and to make our ways and protocols more familiar to the mainstream.

Other research option suggested by the Elders includes health research. One lady Elder suggested that communities research themselves in the area of biological changes in women and to teach the findings to the youth of the community. Another suggested that diabetes research can examine controversial issues such as the ‘extra gene’, or the ‘thrifty gene,’ that is suggested in diabetes discourse. Another suggestion made by the Elders is to do research concerning First Nations attitudes and responses to issues like transplants, amputations, and dialysis. It is suggested that some tribes do not condone these practices and research would uncover the concerns and also gain valuable guidance from Elders on the cultural approaches to these issues. Other issues that could be elucidated by research in First Nations communities could include the sensitivities towards palliative care and chemotherapy.

The research should address the life that is coming for the youth so that they know and respect who they are and for adults to act as role models for the young people to learn the ways of community. They said knowing the story of being is important.

## **5.8 Humanity**

The Elders also discussed the idea of common humanity. They said that our common humanity and our survival was ultimately the purpose for knowledge held by different peoples. At the level of our common humanity, the Elders said there is a need to find commonalities and not to focus on the differences of culture or peoples. We are all human being first and foremost on the global level. The global picture is important, but the Elders also reminded us that there were certain techniques for handling local knowledge and there were other techniques for accumulating knowledge for the human race.

The exposure to a variety of Indigenous cultures is beneficial in coming to an understanding the value of local culture and knowledge in the bigger picture of the global village. Cross cultural work and working with people also requires the value of respect. Respecting other peoples' knowledge is a sincere requirement. Very often cultural postulates are the proper practices when engaged in cross-cultural work. The Western world and religious institutions did not understand this value, as past injustices on Indigenous populations wrought by these institutions would indicate. One Elder stated that, historically, western society had outlawed our Indigenous ceremonies and it now seeks the very same knowledge that is the foundation of these practices. In concert with this respect is the notion of different knowledge in different territories. Respect should be accorded to the people within their territory. Their knowledge is particular to that territory and each community has own way to deal with issues, its own responses, and its own way of understanding. The Elders kept pointing to treaty rights as an example of how western society promises one thing and does not live up to its responsibilities. Treaties are still in place but have not been yet fully implemented and never fully honored by the state. The Elders feel that the mainstream is still intent on doing away with the treaties and presently the treaties are in danger of being eroded. Perhaps they see a similar process of erosion in their knowledge base as well.

The Elders discussed certain values in relation to how the knowledge will be handled. For example they said that people should know the value of giving and how that works in people's lives. In relation to knowledge, the Elders stressed that knowledge should be developed for beneficial purposes and not to do things for the money. For example, the Elders stressed that 'learners' learn the knowledge by internalization acquired through observing first and then learning by action. The Elders also pointed out that 'learners' should have respect for what is not named, the unspoken. Many times the unspoken is the particular knowledge that the Elders do not want to disclose with the expectation that it be left alone.

## **6.0 Elders' Dialogues Summary**

The preceding section deals with the main issues brought out by the Elders in research ethics. As stated, the notion of a knowledge tradition, complete with its luggage of beliefs, context, and processes imposing into another knowledge domain, ad hoc, elicits something improper. This matter of cross-over into different jurisdictions and cultures requires, at the least, a protracted process of dialogue for it to be even considered. In essence, dialogue must become a

central feature of a new relationship between Indigenous Peoples and other traditions of knowledge.

### **6.1 Notion of Dialogue**

The ethical space between cultures offers itself as the theatre for cross-cultural dialogue for the objective of ethically engaging different knowledge systems. According to Bohm (1996), dialogue enables inquiry into processes that can fragment and interfere with real communication between individuals, nations, and even different parts of the same organization. Dialogue is concerned with providing a space for exploring the field of thought and attention is given to understanding how thought functions in governing our cross-cultural behaviors. It is a way of observing, collectively, how hidden values and intentions can control our behavior, and how unnoticed cultural differences can clash without our realizing what is occurring. Cross-cultural research has been problematic because of this neglect for the unseen, unstated influential undercurrent of hidden values and intentions.

Dialogue is essentially a ‘conversation’ between equals and is therefore concerned with exploring the social constructs and inhibitions that affect communications and interaction. The act of dialogue is the act of resolving the confrontation and is itself an ethical act. This will entail the examination of structures and systems in attempts to remove all vestiges of colonial and imperial forms of knowledge production and to instill a respect and understanding of different and multiple readings of the world. It will be in the ethical space where all assumptions, biases, and misrepresentations about the ‘other’ are brought to bear in the interest of identifying ethical/moral principles in cross cultural interaction.

### **6.2 Community Contexts**

Community knowledge has become the space of hope and possibility for Indigenous Peoples in the aftermath of the darkest hours of the mind-numbing ideology wrought by Christianity and its attitudinal derivatives that have been imposed for the last five hundred years. This retreat enables the transformation of knowledge based Indigenous vision with its social and historical dimensions of community experience. Linda Smith (1999) explains:

To resist is to retrench in the margins, retrieve what we were and remake ourselves. The past, our stories local and global, the present, our communities, cultures, languages, and social practices – all may be spaces of marginalization, but they have also become spaces of resistance and hope (p.4).

New frontiers of knowledge that have been ignored and suppressed through the ‘time-lagged colonial moment’ (Bhabha, 1994) need to be nurtured and supported as alternate spaces of knowledge. These are spaces constituted by discourses in Indigenous languages, worldviews, and community aspirations for an ethical order in society – a knowing that contrasts with Western notions of the universal. Particularly difficult terrains of the new dialogue will include how to resolve the issue of contexts, or how to reconcile disparate contexts in which the respective knowledge systems are embedded. This means work to reconcile a scientific based knowledge that defines much of the Western world with an epistemology based on participatory consciousness and personal experiences with human, natural, and supernatural relationships found in Indigenous

learning traditions. Reclaiming voice and reclaiming vision through community models become necessary processes for Indigenous Peoples to re-establish a sense of true identity and to be able to assert the Indigenous mind and discourse in ways that bring honor to the community. In short, this means asserting the sense of Indigenous difference to Western norms and the disassociation from the negative images constructed in Western texts.

The community represents the synthesis of many peoples' search for knowledge at the conjunction of physical and metaphysical realities. The accumulated knowledge of many people developed through many community held processes created a unified consciousness. This consciousness transformed the community into a participatory organism known as community. In doing so, the community, through its people, became empowered as the 'culture' of accumulated knowledge. The people formed the community, and the community formed and held the worldview in its collective form. The knowledge of the people was the glue that held the community together and molded the ethos and the codes that the people would live by.

Indigenous communities are very important for the protection, enhancement and promotion of specific knowledge. Cajete (1994) suggests that, "the community is the place where the forming of the heart and face of the individual as one of the people is most fully expressed" (p. 164). It is primary expression of a natural context and environment where exists the fundamental right of person-hood to be what one is meant to be. Movement within this community context allows individuals to discover all there is to discover about one-self.

This knowledge system encompasses all the aspects of an Indigenous Peoples' learning tradition and provides for the appropriate venues for its dissemination. Although this knowledge is largely unwritten in any text, it remains indelibly etched in our community ethos and in the narratives that that so passionately oriented generations of our ancestors. As Battiste & Barman (1995) write, "history, literature, philosophy, mythology, astrology, and genealogy were all oral disciplines in Indian culture". Whitt (1995) succinctly describes what constitutes a knowledge system. She writes:

[A] knowledge system can be defined in terms of four characteristics: epistemology, a theory of knowledge giving an account of what counts as knowledge and how we know what we know; transmission, dealing with how knowledge is conveyed or acquired, how it is learned and taught; power, both external (how knowledge communities relate to other knowledge communities) and internal (how members of a given knowledge community relate to one another); and innovation, how what counts as knowledge may be changed or modified (p. 231).

The frameworks and models for Indigenous Peoples' emancipation and development are enfolded within the ethos of our communities, in the memories of our Elders, our languages that describe our worldviews, and within our individual and family consciousness and narratives of that consciousness. Indigenous processes for emancipation must be enacted and this entails a re-centering of our historical and social awareness and to recover the integrity of individuals within the rubric of communities. The Indigenous relationship to knowledge is through a complex nexus of communal, natural, and spiritual orders.

### **6.3 Consent**

Consent to research in and by itself is problematic if these larger issues of knowledge contexts remain unresolved. Consent implies a privilege. A privilege created by readily executed apparatus such as funding, research capacity, and intentions coming from the knowledge context. For example, obtaining consent from individuals in Indigenous communities can be problematic for a number of reasons. The Western paradigm of individualism that recognizes the right of the individual to give knowledge through ‘informed consent’ is contradictory to the concept of collective ownership understood by Indigenous Peoples. Linda Smith (1999) points out:

Indigenous groups argue that legal definitions of ethics are framed in ways which contain the Western sense of the individual and of individualized property – for example, the right of an individual to give his or her own knowledge, or the right to give informed consent. The social ‘good’ against which ethical standards are determined is based on the same beliefs about the individual and individual property (p.118).

For one, Henderson (1996) has observed, “no single individual can ever be aware of all the cultural concerns that may exist in the community” (p. 83). These concerns may revolve around the issue of releasing information that is private and sacred to individuals, families and whole communities and any disclosure of such information is a moral transgression against those families and communities. A similar view is asserted by Maddocks (1992) who warns of ‘picking off’ gullible or uncomprehending individuals for opportunistic study. Similarly, Deloria (1980) asserts that “breaking the specialist stranglehold over racial minorities is a critical problem, and this aspect of social science alone makes the discussion of ‘informed consent’ irrelevant” (p. 270). The notion of consent must now be reevaluated in light of arguments presented in later sections of this report.

### **6.4 Empowerment**

Empowerment for Indigenous Peoples through research, according to Bishop (1994), means “decision making from a position of shared strength and wealth, not from a position...of relinquishing one’s language and culture in order to participate in the mainstream” (p. 177). Although there are constraints in place within the Western system for the self-determination of Indigenous researchers and perhaps the development of an Indigenous research methodology, various alternatives for the enabling of Indigenous research have been suggested. King (1989) articulates the need for Indigenous researchers to do research using Indigenous Peoples’ models and concepts. He discusses research constructs and interpretations being carried out according to Indigenous languages and worldviews, and that research should focus on Indigenous Peoples’ knowledge and ways of knowing. In a similar vein, Redhorse, et. al. (1989) note that Indigenous scholars “tease out cultural norms, tribal customs, and intellectual traditions” (p. 268) as an alternative research agenda while Stokes (1985) regards land and language as crucial elements in the survival of Indigenous People and indicates that these should be priorities of research. Whatever the approach Indigenous Peoples decide on, the research programs should realign the purpose and focus of research from frameworks which support Eurocentric values and interests

towards models of research that empower and enable multiple communities to establish their own centers of knowledge. This is an Indigenous research agenda that takes into account not only the values and reality of Indigenous societies but also places front and center the protection of Indigenous knowledge (Stokes, 1985; King, 1989; Darou, et. al., 1993; Redhorse, et. al., 1989). Linda Smith (1999) frames these methodologies of research as reclaiming, re-centering, and re-naming nations. Any researcher that contemplates doing research with indigenous communities may well ask “which knowledge base or archive am I feeding?” Western research has been framed in ways that supports and feeds the dominant system while the indigenous community, as subject, was deprived of its legitimate voice and benefits. The answer to this question should provide the researcher a glimpse of the ethics that Elders talk about.

## **6.5 Public vs Private Knowledge**

These are instances where it becomes problematic to define personal scholarship and a personal claim to knowledge when dealing with Indigenous knowledge. It is therefore to be supposed that the tensions between collective ownership and individual scholarship will require considerable discussion. The collective nature of community knowledge leads to the collective ownership of knowledge in Indigenous communities. Apart from the individualism and the individualistic sense of personal scholarship, in some non-Indigenous societies, collective ownership meant “no ownership” (Peterson, 1982). This has led to the rationale that since there is ‘no ownership’, say of Indigenous Peoples cultural and intellectual property, that this opens the door to ‘state ownership’. The political implication of this rationale is that the assertion of collective knowledge within Indigenous societies has been interpreted by the state to mean ‘no ownership’ because collective rights are not broadly recognized in Western society. In terms of knowledge production within the western domain, this rationale has translated into the concept of state or public ownership of all knowledge and hence the ‘public domain.’ The Elders said that community knowledge is not in the public domain. It is embedded in the Indigenous community, which is under a different jurisdiction, different rules of knowledge production, validation and dissemination than those of western knowledge.

In the interim, should interaction be successfully negotiated between the indigenous community and western institutions, knowledge translation and transfer will be challenging but will require immediate attention. It is important for Indigenous knowledge to be recognized as valid in its own right and not to be dismissed if it contradicts or is not explicable in Western academic terms. It may mean that Western scholarship, as it relates to research involving Indigenous Peoples, will find difficulty in re-examining their truth claims and the possibility of undermining their power and privilege positions in knowledge production by resolving issues of knowledge like ownership, control, benefits and all the other assorted contested issues endemic to the current research order. A level playing field is necessary in building a mutually beneficial relationship. This kind of work must be carefully crafted to foster a mutual appreciation for working together and to pave the way for future endeavours. The Elders’ dialogues described in this paper initiates an exchange, a discussion between the First Nations and western community regarding the importance of knowledge from different perspectives.

## 7.0 Literature Review

The literature review of ethics and research issues pertaining to Indigenous Peoples builds upon a recent review that the IPHRC team conducted for the three granting agencies. Rather than duplicate our own work, we offer here a brief summary of that comprehensive report highlighting, perhaps with a bit more zeal, what we deem to be the more salient issues in the ethics discourse.

The literature review synthesized discussions from the current literature on research ethics and helped to paint a picture of the problematic history of Indigenous research as emerging from multiple social science disciplines that share responsibility for the fall-out of exploitative research. The resistance to research by Aboriginal people, beginning in the 1970s, has led to a wealth of literature by Aboriginal and non-Aboriginal scholars critiquing western research practices as inappropriate for Indigenous issues and disempowering for the people, and condemning “pathologizing” and exploitative research practices. Many authors have provided innovative ideas and visions for cultural relevant and appropriate research methodologies that use as foundational frameworks, Indigenous worldview, and epistemologies. Beginning with participatory action research, arising concurrent to the development of third world critical theory - Freire’s (1970) work being the primary example - research methodologies have moved away from western frameworks imposed by community “outsiders” to “insider” research where the research is community based, participatory, collaborative, and benefits based.

Most recently, with acknowledgement of the Maori scholars as frontrunners in the Indigenous research discourse, we see the attainment of a critical mass worldwide of Indigenous research paradigms founded upon Indigenous worldview, knowledge and protocols. Arising from these paradigms are powerful assertions of Indigenous requirements for research including research guidelines and protocols, research negotiations and agreements, memorandums of understandings, contracts, adherence to Indigenous protocols, and a myriad configurations of collaborative partnerships between researchers (both Indigenous and non), and Indigenous research participants. Even more significant is the articulation of the extreme divergence of Indigenous and Western worldviews as this plays out in knowledge translation, transfer, uptake, and exchange.

It became evident in the course of the literature review, that research with Indigenous peoples is predominantly within the qualitative genre because qualitative research frameworks, according to Denzin & Lincoln (2000) provide “congruence and cultural safety” for the tenets of Indigenous worldview. The “seventh moment of research – the future”, the authors describe, is defined by responsive research geared to the “moral imperatives” of the human community (p.1062) and “ways of knowing” are central to this evolving qualitative discourse (Denzin & Lincoln, 2000). The more inclusive and respectful research becomes of other ways of knowing, the more applicable Western qualitative research is to Indigenous people, and Indigenous issues. The seventh movement, the “unknown terrain” of research, consists of space within the qualitative paradigm, in particular, where Indigenous theory and method are acknowledged as valuable. Denzin (2003) hints that the new era is influenced by feminist and postmodern theories, taking wisdom and guidance from the sacred epistemologies of Indigenous peoples; a pedagogy that will take into account humanity and other ways of knowing.

What was marked formerly by the firm and rigid shapes of a Eurocentric geometry is now the fluid, shape-shifting image of chemical flux and transformation, as margins move to the center, the center moves to the margins, and the whole is reconstituted again in some new form. (Denzin & Lincoln, 2000, p.1063).

We recognize in the literature that research historically drew “upon frameworks, processes and practices of colonial, Western worldviews and the inherent knowledge, methods, morals and beliefs” (Martin, 2001, p.2). Indigenous theories on the other hand, “challenge the hegemony of Western theoretical production” (Pillai, 1996, p. 218). Challenging research hegemony involves understanding colonial history, and ensuring that research has practical applications that empower and liberate the people through practical and ameliorative results; which, in contemporary Indigenous contexts, means engaging in the decolonization agenda; that is, the research agenda for Aboriginal people is very specifically directed towards the amelioration of the impact of those dynamics. In the contemporary context, the research agenda comprises political, emancipatory, and ameliorative objectives (Sinclair, 2003). The concept of the ethical space provides a venue within which to articulate the possibilities and challenges of bringing together different ways of coming to knowledge and applying this theory to the practice of research (Ermine, Sinclair & Jeffery, 2004). We now turn to a discussion of the recent efforts on behalf of the federal funding agencies and the Interagency Advisory Panel on Research (PRE) to revise their ethics guidelines and protocols, in consultation and collaboration with Aboriginal communities.

## **8.0 Ethics Revisioning**

The Interagency Advisory Panel on Research Ethics (“PRE”) was created by the three main Canadian governmental organizations that fund scientific and social research. The PRE has launched a consultation on research ethical standards for research in or involving Aboriginal people or communities in the following terms:

There is growing recognition that some research involving Aboriginal individuals may also involve the communities or groups to which they belong. The Councils affirm that in developing ethical standards and practices, Aboriginal peoples have rights and interests which deserve recognition and respect by the research community. This Section thus has three aims: to assist researchers and REBs in determining which projects might involve research on such groups; to illustrate ethical issues and conduct for such research; and to indicate good practices that researchers should consider.<sup>2</sup>

Smith (1999), articulates her reality in relation to research in her communities:

[I] grew up within Indigenous communities where stories about research and particularly about researchers (the human carriers of research) were intertwined with stories about all other forms of colonization and injustice. These were cautionary tales where the surface story was not as important as the underlying examples of cultural protocols broken, values

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<sup>2</sup> Tri-Council Policy Statement, *Ethical Conduct for Research Involving Humans*, Ottawa: Medical Research Council of Canada, 2003 at p. 6.1.

negated, small tests failed and key people ignored. The greater danger, however, was in the creeping policies that intruded into every aspect of our lives, legitimated by research, informed more often by ideology. (p. 5)

The Panel on Research Ethics has published ethics standards and procedures for all research involving humans funded by any of its creating agencies. While the bulk of the policy statement is thorough and detailed, the PRE states that the material addressing research in Aboriginal communities is at an early stage of development. The Panel acknowledges it may be appropriate to establish policies for research involving Aboriginal Peoples, and that any such policy should be developed with input from Aboriginal communities and representatives, and also from non-Aboriginal organizations and researchers. In the policy guide, the Panel offers an overview of the issues relating to Aboriginal peoples from the PRE's perspective, and the Panel identifies numerous practices to consider when conducting research in and with Aboriginal communities.

In its preliminary paper the PRE did not attempt to describe the process or the criteria they will use in developing this new standard. The PRE states the ethics guidelines produced as a result of this process will do three things: (a) it will give researchers and research ethics boards a tool to discern what research proposals involve Aboriginal peoples, that is, what projects trigger the application of these standards, (b) it will illustrate appropriate ethics and methodology for research involving Aboriginal communities, and (c) it will contain a list of good practices that researchers should consider.

The PRE did not clarify what process it is using in developing a new standard. For example, how will it reconcile radically different opinions about the extent of the issues? Will First Nations governments and political organizations be invited to participate in this process? Or will the PRE presume that First Nations have no jurisdiction over their own people, their traditional or Treaty lands, the plants growing on the lands, and the fish in the water?<sup>3</sup> How will the PRE determine policy when different opinions are held by researchers and research-affiliated bodies with different worldviews, for example, on the issue of whether compliance with the standards is mandatory or at the discretion of the researcher? What process can all interested parties accept? The PRE has already taken some positions as to the significance of the new policy on research involving Aboriginal peoples. Specifically, the Policy Statement clarifies that the new policy will add requirements to projects – nothing in the policy will supercede the rest of the ethical standards or procedures for research. This raises the question of what if a substantial body of researchers and bodies functioning in an Aboriginal world view question some of these established positions? It doesn't appear that the PRE has not publicized a statement about the process of review which is of fundamental concern to anyone who is wants to build full accountability into the research process – accountability both to the research ethics boards, but also to local Aboriginal authorities.

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<sup>3</sup> The IPHRC Report discusses the centrality of the issue of jurisdiction in this policy review process. To clarify: "Jurisdiction therefore refers to the rights of nations as to their heritage, cultural and intellectual property, languages, and religion amongst other items. ... A starting point when articulating research ethics with respect to Indigenous Peoples must be the law and customs of the Indigenous Peoples involved. The national Aboriginal Health Organization states that these laws and customs "define what constitutes property, identifies who has the right to share knowledge and determines who is to benefit and be responsible for the sharing." (p. 39-40)

## 8.1 Worldview

The PRE has embarked on this process of policy review, inviting interested persons and organizations to contribute to the discussion as to the ideal contents of a policy addressing ethical standards for research in Aboriginal communities. In terms of the process alone, given the history of research “[undermining] Indigenous Peoples’ empowerment and self-dependence”, the interests, values, and experiences of Aboriginal researchers and communities who have experience with research must be focal points of the PRE’s policy development process. (Ermine, Sinclair and Jeffery, 2004, p. 12)

The PRE must address the reality that Aboriginal cultures are based on fundamentally different worldviews than the Western tradition. Academics trained uncritically in the Western liberal tradition have systematically and radically different ideas from people socialized in Aboriginal traditions about what it means to be human, what our relationships with others in our family and community are and should be, and what our individual and collective responsibilities are to one another, to other communities, to the land, and to other species. The following quotation draws on the work of Jerry Mander, and notes some of extremely general trends in Aboriginal world views and the Western world views:

In terms of economics, the Native peoples tend to have communal property, subsistence production, barter systems, high-impact technology, and competitive production. In terms of political relations, Native people have consensual processes, direct “participatory” democracy, and laws embedded in oral traditions. On the other hand, modern society has centralized executive authorities, representative democracy, and written laws. In respect to their social relations, they differ, generally, in terms of matrilineality versus patriarchy, extended versus nuclear families, and low versus high population density. Finally, regarding differences in worldview, the Native peoples are polytheistic, derive an understanding of the world from the natural order’s rhythms and cycles of life, and include animals and plants as well as other natural features in their conceptions of spirituality, which the cultural anthropologists call animism and totemism. (M.A. Jaimes, 1995, 275)

In addition to structuring economic systems, social relations, political structures and spiritual practices, worldviews include norms about how knowledge can and should be transmitted, held and received, and by whom, which norms have obvious relevance to research enterprises. Part of what Indigenous communities may be considering when contemplating participation in a research project, is whether systems can be put in place to ensure that knowledge that is shared will be in hands where the Aboriginal protocols of the particular people will be followed. If a community attempts to do that with a research contract, for example, the concepts of Canadian/non-Aboriginal law will limit what can be enforced under a breach of contract.

## 8.2 Consultation and Accommodation

The submissions to the PRE by and on behalf of Indigenous researchers and organizations must receive more than consideration. In the context of governments intruding on Aboriginal rights, the Supreme Court of Canada has stated that authorities must do more than consult with Aboriginals whose rights are affected. Governments must actually accommodate those interests. A summary of a recent case on the legal necessity of consulting with Aboriginal people will shed light on this point.

In *Haida Nation v. British Columbia (Minister of Forests)* the Government of British Columbia issued a license to Weyerhaeuser Ltd. to harvest trees on certain lands. Although the Haida asserted Aboriginal title to the lands covered in the license, the government issued the tree forest license without even discussing the matter with the First Nation. The Haida sued, alleging even though the Haida have not yet established their Aboriginal title in Canadian court, the Crown knew the Haida asserted authority over the lands and so the Crown ought to have consulted with the Haida. The Supreme Court of Canada agreed:

16 The government's duty to consult with Aboriginal peoples and accommodate their interests is grounded in the honour of the Crown. The honour of the Crown is always at stake in its dealings with Aboriginal peoples: see for example [R. v. Badger](#), [1996] 1 S.C.R. 771, at para. 41; [R. v. Marshall](#), [1999] 3 S.C.R. 456. It is not a mere incantation, but rather a core precept that finds its application in concrete practices.

17 The historical roots of the principle of the honour of the Crown suggest that it must be understood generously in order to reflect the underlying realities from which it stems. In all its dealings with Aboriginal peoples, from the assertion of sovereignty to the resolution of claims and the implementation of treaties, the Crown must act honourably. Nothing less is required if we are to achieve "the reconciliation of the pre-existence of Aboriginal societies with the sovereignty of the Crown": [Delgamuukw](#), *supra*, at para. 186, quoting [Van der Peet](#), *supra*, at para. 31.

18 The honour of the Crown gives rise to different duties in different circumstances. Where the Crown has assumed discretionary control over specific Aboriginal interests, the honour of the Crown gives rise to a fiduciary duty: [Wewaykum Indian Band v. Canada](#), [2002] 4 S.C.R. 245, 2002 SCC 79, at para. 79. The content of the fiduciary duty may vary to take into account the Crown's other, broader obligations. However, the duty's fulfilment requires that the Crown act with reference to the Aboriginal group's best interest in exercising discretionary control over the specific Aboriginal interest at stake.<sup>4</sup>

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<sup>4</sup> *Haida Nation v. British Columbia (Minister of Forests)*, 2004 SCC 73.

With this origin of the duty clarified, the Court continued, explaining the nature and scope of the duty to consult where the First Nation asserts a property right, and the government gives others licenses to take some of the claimed property, in this instance, trees.

Is the Crown, under the aegis of its asserted sovereignty, entitled to use the resources at issue as it chooses, pending proof and resolution of the Aboriginal claim? Or must it adjust its conduct to reflect the as yet unresolved rights claimed by the Aboriginal claimants?

27 The answer, once again, lies in the honour of the Crown. The Crown, acting honourably, cannot cavalierly run roughshod over Aboriginal interests where claims affecting these interests are being seriously pursued in the process of treaty negotiation and proof. It must respect these potential, but yet unproven, interests. The Crown is not rendered impotent. It may continue to manage the resource in question pending claims resolution. But, depending on the circumstances, discussed more fully below, the honour of the Crown may require it to consult with and reasonably accommodate Aboriginal interests pending resolution of the claim. To unilaterally exploit a claimed resource during the process of proving and resolving the Aboriginal claim to that resource, may be to deprive the Aboriginal claimants of some or all of the benefit of the resource. That is not honourable.

32 The jurisprudence of this Court supports the view that the duty to consult and accommodate is part of a process of fair dealing and reconciliation that begins with the assertion of sovereignty and continues beyond formal claims resolution. Reconciliation is not a final legal remedy in the usual sense. Rather, it is a process flowing from rights guaranteed by s. 35(1) of the *Constitution Act, 1982*. This process of reconciliation flows from the Crown's duty of honourable dealing toward Aboriginal peoples, which arises in turn from the Crown's assertion of sovereignty over an Aboriginal people and *de facto* control of land and resources that were formerly in the control of that people. As stated in [Mitchell v. M.N.R., \[2001\] 1 S.C.R. 911](#), 2001 SCC 33, at para. 9, "[w]ith this assertion [sovereignty] arose an obligation to treat Aboriginal peoples fairly and honourably, and to protect them from exploitation . . ." (emphasis added).

33 To limit reconciliation to the post-proof sphere risks treating reconciliation as a distant legalistic goal, devoid of the "meaningful content" mandated by the "solemn commitment" made by the Crown in recognizing and affirming Aboriginal rights and title: [Sparrow, supra](#), at p. 1108. It also risks unfortunate consequences. When the distant goal of proof is finally reached, the Aboriginal peoples may find their land and resources changed and denuded. This is not reconciliation. Nor is it honourable.

...

35 But, when precisely does a duty to consult arise? The foundation of the duty in the Crown's honour and the goal of reconciliation, suggest that the duty arises when

the Crown has knowledge, real or constructive, of the potential existence of the Aboriginal right or title and contemplates conduct that might adversely affect it.

42 At all stages, good faith on both sides is required. The common thread on the Crown's part must be "the intention of substantially addressing [Aboriginal] concerns" as they are raised (*Delgamuukw, supra*, at para. 168), through a meaningful process of consultation.

In *Haida*, the Crown was found to have an obligation to consult where it was merely issuing licenses to harvest trees. The Crown itself was neither funding nor participating in the conduct that the First Nation objected to. In the case of academic research, the Tri-Council funds research, sets standards for the legal and ethical conduct of research in all of Canada, on First Nations lands and off. At the same time, Indigenous Peoples within Canada are asserting jurisdiction and ownership of traditional lands and Treaty lands, of cultural and intellectual property, traditional uses of plants, as well as jurisdiction over their citizens. To acknowledge and respect this jurisdiction, the Panel must seek input from Indigenous communities in developing the new policy and must also address the interests asserted by Aboriginal researchers and communities in the new policy. It does not matter that the Indigenous groups have not established their jurisdiction or ownership in Canadian courts. The Aboriginal communities assert jurisdiction and ownership, and the funding agencies know as much.

There is a strong basis in law for funding agencies to be legally and constitutionally obligated to address the substantial concerns of Aboriginal communities and researchers in the new policy. As well, on another level, the PRE has a basis in law and history to set up a research infrastructure, which recognizes that Indigenous Peoples are asserting jurisdiction over, *and* ownership of traditional lands and traditional knowledge. Regardless of whether any First Nation has proven these interests in court, once Indigenous group asserts the rights, the Crown must consider the nature of the rights asserted before making any decisions that would affect the full enjoyment of those rights.

In this consultation, the PRE seeks to consider and institutionalize proper respect for Indigenous cultures and traditions in research projects proposed by Aboriginal and non-Aboriginal researchers alike. The views and experiences of Indigenous researchers and communities must receive weight and deference by the PRE. As well, the PRE must incorporate the substance of these submissions into the policy. Consultation without any accommodation, or with only minimal accommodation shows the request for consultation was not genuine, and was intended to accomplish political purposes rather than to transform the PRE into an agency that is taking initiative in participating in the new era of research in and about Aboriginal communities.

### **8.3 “Respect for Human Dignity” and World View**

The current Tri-Council Policy identifies “respect for human dignity” as a moral imperative and a cornerstone of their ethics framework (i.4). Obstacles arise immediately in cross-cultural contexts and in research across cultures. For example, both respect and human dignity have various meanings in different cultures, and the norms for treating people with respect and dignity

vary as a function of this. An unprepared non-Aboriginal researcher arriving in a Cree community, for example, to propose a research project would likely inadvertently violate a number of Cree principles about human dignity. This may both harm the community and undermine an important research project. The PRE states that human dignity includes physical, psychological, and cultural integrity. Conversations must occur between institutions setting ethical standards, Aboriginal and non-Aboriginal researchers and Aboriginal communities about what these terms mean and what it looks like when someone is treating another with dignity. The PRE, and other research bodies, must not assume its idea of “respect for human dignity” is transparent and applicable across cultures, or universal among cultures. In this manner, the application of the TCPS to research projects involving Aboriginal populations requires the entire document to be read in a different light, and with regard to the implicit cultural values and norms.

#### **8.4 Communication and Translation between Worldviews**

In the literature addressing cross-cultural research, authors express a wide range of views about whether or how conversations across worldviews are possible. Some believe that all terms in a language or culture derive their full meaning from the rest of the language, from the contexts they are typically used in, from the cultural values and practices, and from the world view of which it forms part. Then between radically different world views, one can see that conversations become difficult because the speakers use words of the language with cultural assumptions – inevitably one is translating every word and attempting to capture its meaning in a foreign tongue with variant cultural undertones to the concepts. From this perspective, conversations between people with different worldviews are impossible, at least in terms of legitimacy – the languages cannot be approximately or perfectly translated into one another, so true and genuine mutual understanding is not possible. At the other end of the extreme, one finds the Western academic tradition, and others, who espouse the view that all languages can be completely and accurately translated into one another without any loss of nuance, tone or significance. Then all languages have the same pattern and can be laid over one another transparently, as templates. This is one of the assumptions that has facilitated the domination of one culture by another. This view is attractive in its simplicity – suddenly cross-cultural work is not difficult if we have skilful translators.

The moderate view recognizes that perfect translation is not possible, but also that we can achieve some degree understanding of the meaning of similar terms in different world views by exchanging more and more information about the place of the term in the world view. So given the PRE value of respect for human dignity in research, what exactly does it mean; what does a researcher do to comply with this requirement? And what does human dignity mean in the Aboriginal culture that the researcher intends to conduct research in? How must the researcher act to show this respect? The concept of the ethical space is a significant avenue for addressing these issues and we assert that there are concepts in the western legal tradition that support the ethical space development project as outlined in the IPHRC (2004) ethics report.

For example, one serious and daunting challenge facing the non-Indigenous researcher is how to fully understand the complexities of the issues within another culture, and to have self-awareness about the extent that the Western cultural lens colours the data and analysis. In a paper entitled, “Living Together: Gitksan Legal Reasoning as a Foundation for Consent”, Val Napoleon

examines customary law among the Gitksan of northwestern British Columbia, by examining how legal reasoning was used in managing and resolving a serious dispute between clans early in the century. She cautions readers about forming oversimple views about what customary law is, and how it operates. Even legal reasoning varies with culture; her paper provides very specific cautions which can be generalized to researchers and research ethics boards dealing with projects in Indigenous communities.

[C]ustomary law inheres in each Aboriginal cultural system as a whole, forming legal orders that enable large groups of people to live together and to manage themselves accordingly. Failure to fully appreciate the complexities and intellectual processes involved with decision making, law making, dispute resolution, and conflict management in Aboriginal legal orders can render Aboriginal cultures into unfortunate, one-dimensional caricatures. In other words, simplistic characterization of Aboriginal legal orders not only ignores history and constant cultural change, it flattens the diversity of cultures and obscures the tremendous depth and scope of human experience.

Among the challenges, especially for non-Indigenous researchers, is to earn the trust and good will in the community that will give the community an incentive to share the complexities of the subject under inquiry. If the researcher's relationship with the Indigenous individuals is merely a means to an end – producing a report to meet some personal academic, commercial or professional goal – then community members might well perceive this and “dumb down” or be deliberately untruthful in their responses – skewing the research data and any analysis based on it.

## **8.5 Diversity Between First Nations and Aboriginal communities**

One cautionary point will be trite to Aboriginal readers and may not be so obvious to others. In the discussions in the research community with respect to this new policy, one must not presume that First Nations or Aboriginal communities are homogenous and that all would accept a generalized policy statement as adequately protecting every community's interests. While the precedents from Australia, New Zealand and North America may be instructive, it is suggested they not be a substitute for individual researchers having to determine local Indigenous norms and research ethics board from having to ensure the researcher functions within the TCPS and the particular Indigenous norms as expressed in a research agreement with the community or otherwise. The point is that the PRE must recognize the authority of Indigenous communities to set their own research protocols covering both ethics and methodology.

## **8.6 World View, Ethical Standards, and Methodologies**

### **A. Ethical Standards**

#### **(i) Property Issues in Relation to Data**

With these complexities and the historical role of research in creating and justifying systemic oppression, the academic values of transparency, accountability, and the clarification of issues relating to ownership, control, access, and possession both of data and of analyses of data become crucial. The Report of the IPHRC to the PRE has canvassed the literature expressing concern for ownership, control, access, and possession of research data.

Ownership, control, access, and possession (OCAP) are all terms relating to one's legal relationship to property. In addition, these concepts are also related to accountability. OCAP collectively are means to ensure researchers fulfill the undertakings made in the research agreement, and that they do not use the data for purposes other than those agreed. Some literature raises OCAP only in relation to data, and not in relation to products of the research – namely, analysis of the data and reporting. In some instances, communities or participants and researchers have agreed that they will share the property interest in the final product. Obviously the agreement creating this joint ownership would also need to clarify the parameters of what this joint ownership means – that is, what rights can the Aboriginal community exercise if they reject the analysis or report, and what rights the researcher can exercise in that instance?

These issues raise broader concerns expressed in the PRE policy relating to academic freedom, which in this context, might be explained as the “right” of a researcher to draw any conclusion he or she sees fit based on the data.

#### **(ii) Transparency and Accountability**

Transparency is an academic virtue that has emerged out of social science research, where the academic community is readily accepting that the interests, identity, values, social-economic place and culture of every researcher inform their decisions to investigate a particular issue.<sup>5</sup> Ought researchers in natural and medical sciences also address transparency issues? What legitimate interest could a researcher have in not being open about their relationship to a specific research enterprise? We suggest no such valid reason for secrecy exists. This also provides a relevant criterion when considering proposals by two or more researchers to enter and investigate an issue in an Aboriginal community. If one proposal involves a person with a historic or family connection to the community, that could serve to enhance the usual systems of accountability and perhaps enable the researcher to draw on existing relationships and knowledge of the community.

Accountability occupies a central place in these research projects, when we have rejected the traditional ideal that the researcher's relationships with subjects ends when data collection is complete. The existing protocols for research in Aboriginal communities recognize long-term

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<sup>5</sup> See for example, the Harvard School of Public Health's Ethical Guidelines for Social Science Research in Health, Part III, which state: 2.5. Researchers should ensure that there is honesty and transparency at every stage of research as these are indispensable for good and ethical research. (at [hsph.harvard.edu](http://hsph.harvard.edu))

accountability to the community is important, and effect this by various means. More generally, researchers have suggested all community-based research can benefit from putting greater demands on researchers for accountability to research participants and to the communities (Downie, 2001).

**(iii) Academic Freedom (p. 8)**

The university has involved a decentralized system of authority in which each individual researcher has defined his or her own road to truth - and the notion of academic freedom requires that we accept that - and where each person plays his or her own role in mentoring a new generation of scholars, whose main job is to simultaneously stand on our shoulders while chopping out all our beliefs at the knees.<sup>6</sup>

Part of the challenge facing the PRE will be grappling with academic freedom, which is a fundamental value in universities, but is viewed with suspicion by many researchers and others on the margins. Academic freedom is the notion that any person has a right to inquire into any subject and ask any questions without concomitant responsibility to follow protocols or be accountable to those answering the questions. Accountability happens only after the analysis is published. And the only form of accountability in the Western academic tradition is peer review; that is, a consideration of the data and analysis by researchers and academics in the same field of study. There is, and some would say must be, no accountability beyond this realm. This ideological foundation of research overlooks the many personal interests of researchers. Ruth Miller (2003) describes the interests of researchers who are physicians, conducting clinical trials, often thought to be the domain of hard science:

Patients enter research trials expecting that the researcher, like their physician, has their best interests in mind. However, researchers have multiple motivations. Researchers are interested in the therapies' potential benefits to future patients, as well as to the research subject. Researchers may have financial incentives to conduct research and to ensure that the research results reflect well on the sponsoring company. The researcher is interested in being the first to publish this research, which will gain him greater recognition, research grants, and career advancement than others in the field who publish later. In some cases, the researcher may also be able to obtain patent rights to the product that he is testing.

The researcher may also feel pressure from his employer institution. The research institution is interested in publishing the best research and hiring the best researchers, so that it can obtain more money from manufacturers and increase its prestige. Institutions take a percentage of all faculty research revenues, as well.

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<sup>6</sup> Ted Palys, "Bulldozers in the Garden: Comments Regarding the Tri-Council Working Group's July 1997 Draft *Code of Ethical Conduct for Research Involving Humans*. <http://www.sfu.ca/~palys/tcwg97.htm>

Despite these incentives for the researcher to pursue a clinical trial, the potential benefit to individual research subjects is uncertain, and the researchers know this. (p. 8)

This is an example of liberal individualism, where personal autonomy is primary and relationships have only secondary importance. The Western worldview underlying much academic research is founded on academic freedom on an ideological level. Simply put, academic freedom is inconsistent with accountability to a community who participated in developing the research and who participated in the research. The PRE must reconcile academic freedom with accountability.

Natural and biomedical scientists might object that their research is immune from values or politics, unlike social sciences. On this basis, researchers in so-called hard science might resist the need to politicize or problematize research development processes and research methodologies. In an article, “Becoming a Mercury Dealer: Moral Implications and the Construction of Objective Knowledge for the James Bay Cree”, Richard Scott explains how epidemiological research into the effects of methylmercury contamination on the people in a Cree community in northern Quebec – the Chisasibi – has political underpinnings, political dimensions and political consequences:

[T]wo politically significant paradoxes [arise] from that research. The first paradox is that, in spite of the fact that nobody in Chisasibi is free from the knowledge that she is contaminated by mercury, in spite of the prominence of media representations that portray the inhabitants of the village as afflicted by the *disease* caused by mercury contamination, and in spite of the presence of a conspicuous medical surveillance program, nobody – neither the people who live there nor the doctors who run the local hospital and the mercury surveillance program – claims to know personally anyone afflicted by methylmercury, nor, indeed, to know confidently what form of disease it might take. The second paradox is that scientific attempts to extract an essential set of objective value-free facts about methylmercury have played a central role in producing methylmercury as a value-laden, fearful, and ambiguous object of knowledge for the people of the community.

Attempts to abstract research out of politics are wrong-headed and deserve suspicion. To understand the real and potential harm of a research hypothesis and a research project, it must be examined through various lenses – the liberal academic lens, the legal lens, and the lens of the participants where those participants are Aboriginal and assert a cultural, legal or other interest in the matter being studied.

## **B. Appropriate Methodology**

### **(i) “Accurate and Informed” Research**

In two passages, the PRE’s policy outline suggests the new policy will seek to promote “accurate and informed research”. The repetition of this phrase implies that the PRE has found part of the historical problem has been inaccurate or uninformed research. That may well be true. However, many will find the faults and solutions to lie at a more fundamental level. That is, the PRE ought to make room in its ethics standards and in research methodology for culture-based

differences. Those differences will be as rigorous and demanding as existing guidelines, though perhaps in different ways. For example, IPHRC has written about the manner in which the Western notion of informed consent must be adapted for research of this type; to permit researchers to establish relationships and trust, and to explain the nature and significance of the proposed research before seeking individual and community assent to participation.

When the PRE asks what characterizes a methodologically and ethically sound research project involving an Aboriginal community, the question, do they mean “ethical” within the Western academic tradition or “ethical” with regard to the local Aboriginal tradition, is critical. The question only makes sense with the acknowledgement that the tradition based on objectivity and distance between inquirer and subject is no longer tenable. The standards must be modified to ensure well-intentioned researchers do not run awry of local norms and protocols.

## **(ii) Local Protocols for Methodology**

Accordingly, the PRE may choose to set a framework of default procedures and values to be used by researchers developing or conducting research projects in Aboriginal communities. But wherever a First Nation, a tribal council consisting of several Nations, or any collective organization adopts protocols for conducting research of their people, their traditional medicines, or on their lands, the PRE must require researchers to abide by those local procedures and standards. This entails that in developing a research proposal, researchers must inquire with the relevant Aboriginal authorities as to whether guidelines have been established, and what traditional *or modern* protocols the people have in place. If there are local protocols, those standards ought to displace the PRE default procedures. In addition, on issues where the local material is silent, then the PRE protocol ought to stand. In the same way the funding and research monitoring agencies attend to applicable federal and provincial laws for a project, another level of law-making authority must be institutionalized in the ethics and funding review process.

If the PRE policy does not *require* researchers to check with local Aboriginal governments and Elders, the PRE may inadvertently fund and facilitate researchers working without any regard for local laws or policies. Following First Nation’s values and norms (norms sufficiently important to have been entrenched in research protocols) is integral to respecting the human dignity of a People who have governed themselves and their lands for millennia.

To illustrate a basic methodological point, in Indigenous cultures a researcher cannot ask an Indigenous person to answer any question that the researcher can think of. Even the mere act of asking can be disrespectful and inappropriate. Often there are protocols that anyone – Indigenous or not – must go through before requesting information. One must not presume that gifts of tobacco and ribbons entitle a researcher to ask anything of an Indigenous person. In the Western tradition, which includes academic research, a researcher can ask virtually any question of a participant, without concern that (a) the mere asking was inappropriate, or that (b) the researcher is not entitled to the information, for procedural, spiritual or cultural reasons.

Including local Indigenous protocols in research methodology adds layers of complexity that may or may not be immediately apparent. For example, a Cree Elder was recently hired by a First Nations government to gather information from other Cree Elders on a specific aspect of Cree

culture. The researcher was asking questions in a circle of Elders, and the entire discussion was in Cree. At one point in the discussion, one Elder expressed profound doubt about whether knowledge about such a sacred subject should be shared and recorded in this way. The information may or may not eventually be public or be used in developing policy. “I think it’s terrible we’re sitting here talking about this. You can’t just have this.” The Cree researcher explained that the person did not believe it appropriate to be having the discussion – teachings were to be shared when a person needed the information and when the person had followed the proper protocols. In this context, protocols may be in-the-moment customs or they may consist of years of hands-on training.

The point being made was a methodological one, is one that is arising repeatedly in research ethics discussions, and illustrates divergence of worldviews in the realm of knowledge pedagogy. While the Elders had different opinions about what was appropriate on that particular day, there can be no doubt that they shared methodological and pedagogical traditions outside the Western one typified in academic research. The information was too important to the community and the culture to be giving it away in this manner. The liberal academic tradition has no parallel limits on appropriate research, so protocols must be included to make room for these types of objections to entire research projects, and to specific questions within an otherwise acceptable research project.

On a related point, soon after the first incident of an Elder objecting to the project, the same researcher was in another community, again hired to seek information from Elders. The Aboriginal body seeking the information provided the researcher with a list of questions to be asked of each Elder participating. In this instance the Elders answered the questions, and when he was done the researcher expressed frustration because the Elders’ answers seemed disjointed and seemed to jump around in a way that did not make sense to him. He explained that this was not the way his People convey knowledge. The question/answer method was not getting the desired result. The researcher then stated he was confident that if he had gone through the protocols for requesting this knowledge then the Elders would share the knowledge in a way that cohered and made sense to him. To be clear, the researcher gave gifts to the Elders, so that general protocol was followed. Rather, the proper protocol would have involved a procedure that took hours or days, perhaps even months or years. This illustrates that Aboriginal as well as non-Aboriginal researchers face challenges in conducting research that follows Western standards and also yields desired information/data in a way that it can be readily analyzed or synthesized.

### **(iii) Default Methodology Protocols**

In several passages, the PRE’s preliminary outline for the new policy contains language that suggests that compliance with the new standards will be optional. (TCP, 6.1, 6.4) For example, the policy suggests researchers “should consider” a number of good practices. In contrast, the policies regarding research involving women and involving incompetent persons are all mandatory (5.3, 5.4) Insofar as the practices are entrenched in policy to protect the community and the researcher then they ought to be mandatory. Given that researchers have interests other than complying with ethical guidelines, such as limited funding and deadlines for producing or publishing reports, it must be clear to researchers that non-compliance is not an option. If the funding agencies sincerely want to end the era of exploitative research – recognizing of course that

exploitation can occur whether or not the researcher had malicious intent – then more than good intentions are necessary. As a matter of policy, researchers must find out the traditions and protocols of the local First Nation or other Indigenous community and follow them. Future generations of researchers must be told unequivocally that a signature on a consent form is not sufficient, for example. Crucial legal issues such as ownership of data, tissue samples, and analysis of data must be addressed. *If the standards are mere suggestions, then they are not standards at all.* It may be appropriate for research ethics boards and researchers to decide what ethical criteria are appropriate for a project, but a researcher must not be permitted to conduct research that contravenes a community's established and publicized research protocols.

It is becoming self-evident that the views expressed here entail that research in an Aboriginal community may be substantially more demanding than research in other communities – in preparation, such as relationship-building and establishing trust to facilitate getting informed consent, and so in the long term accountability of the researcher to the community for the use of the data and analysis. This may include legal co-ownership of the data and/or analysis if the researcher and community so choose. The altered research process that may require embracing these values, and deep respect, may also require a researcher to commit to a relationship with an Indigenous community that spans many years.

If the suggested changes impede the flow of researchers into Indigenous communities then so be it. The existing ethical standards have been grossly inadequate, at the very minimum, to ensure researchers did not harm Indigenous individuals or communities. A new policy must do far more. It must actually ensure all research projects provide benefit to the community and acknowledge the authority of Aboriginal communities over the community's people, lands, values, traditions, and knowledge.

#### **iv. The Scope of the New Policy**

From the brief summary of the PRE's position on research involving Indigenous peoples, it appears the PRE may see the only current issue is what projects have dimensions which involve or affect the collective interests of an Aboriginal community. Recall the PRE's three purposes of the chapter are to develop criteria for discerning what research triggers some consideration of community interests, to illustrate examples of ethical issues, and to suggest good practices. The Report of the IPHRC synthesizes the views of many authors that the scope of the problem goes far beyond, "when and how to seek community input". The basic tenets of academic research must be examined and revised, maintaining all standards of excellence and looking at research projects and research agendas generally, through an Indigenous worldview, to determine where the system must change. Both ethical standards and methodological practices and assumptions must be discussed in the community, with a view to increase mutual understanding, and reach a workable, rigorous accommodation of the interests of community-based researchers, and academics entrenched in the Western worldview. This discussion can also be characterized as between those disenchanted with the notion of "pure research", and those who continue believe in the intrinsic value and political neutrality of "pure research". For the conversation to be truly equal, we must acknowledge the historic dynamics of the power relationships and the way "rationality", "objectivity", "rigour", and other such notions have been used by those in power to deny the legitimacy of dissenting voices. Researchers, academics, and funding agency personnel truly operate from the ethical space.

The Interagency Advisory Panel has accurately identified this time as a time of opportunities for researchers and research ethics boards to develop relationships with Aboriginal communities, a time when Indigenous peoples are developing research protocols which will serve as clarifying the parameters for research involving the community. Indeed, the revisioning of the research process requires a willingness to explore many new avenues. One such avenue includes emerging legal implications of an altered research process. We turn now to an exploration of those issues.

## **9.0 Liability Issues in Community-Based Research in and about Indigenous Populations**

This section consists of a discussion of liability in research involving Aboriginal communities. IPHRC recognizes that any re-ordering of research ethics guidelines must also be informed by an understanding of the legal implications of the new framework. To be clear, the legal implications of a new Tri-Council Policy on research ethics involving Aboriginal peoples are not any more important than the social consequences of the policy, or the impact of acknowledging the power relationships in research. The legal aspect is one consideration among many that institutions and communities must be aware of when participating in the development of new research policies. Further, this legal analysis is intended to be helpful to individuals and communities developing research protocols, creating funding guidelines for research, and in drafting research agreements between researchers and community participants in research involving Aboriginal peoples.<sup>7</sup>

As Aboriginal governments and communities assume a greater degree of control of research conducted within their boundaries or involving their people, several legal and insurance issues need to be addressed. Insurance policies that covered university-affiliated research do not apply, and so all involved must be aware of the risks and make informed decisions about risk management. A related challenge arises relating to research ethics boards, which will be a secondary but important theme in this section. Before discussing the nature of these particular issues, and available solutions, a brief summary of the relevant laws relating to liability in conducting research as offered.

A researcher may be held liable for misconduct during a research project under any or several of the following categories: (a) liability for breach of contract – for example, a funding agreement or a research agreement, (b) liability in negligence – where someone did not fulfill a duty of care owed to another who suffered injury or other damages from the negligence, and (c) malpractice – where a professional person did not fulfill the standard of conduct expected of a person in that situation, and (d) liability for battery – a non-criminal assault, and (e) fiduciary obligation – which arises where one is in a vulnerable position because another has exclusive power over some aspect of the person or her property.<sup>8</sup> Where a community believes it suffered injury arising from research, the community probably lacks the required legal capacity to sue, as a

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<sup>7</sup> This paper is not legal advice. Anyone who is making a decision about how to handle an issue with legal dimensions should seek legal advice on their particular situation.

<sup>8</sup> Researchers are also open to criminal prosecutions, and civil actions for wrongful death, and intentional infliction of shock. Criminal prosecutions are rare according to the Medical Research Council of Canada Working Group on Liability, “Report of the Working Group on Liability” (1991) at 15 [unpublished].

community. *If a community is a First Nation, then as a “band” under the Indian Act, it will have some legal capacities.* These main categories of liability will be discussed in turn.

## **9.1 Liability in Contract**

A person will be liable in contract where he or she expressly or impliedly agreed to do something, and where another person exchanged something of value for that undertaking. Then the person who does not fulfill their promise, that person will be obligated to pay the other for costs incurred relying on the promise or compensate for lost monies. Damages are calculated solely on the basis of the negative financial consequences of the broken contract. Any injury that cannot be quantified in the marketplace is not compensable.

In research contexts several kinds of contractual breaches may be typical based on the two main kinds of contracts involved – research agreements and funding agreements.

Recently, it becoming common practice for some researchers to use “Memoranda of Understanding”(MOU) for research agreements to clarify the roles and expectations of the researcher and participants. A memorandum of understanding is not a contract, and cannot be enforced by a court. An MOU does not give anyone rights to anything, and so cannot form the basis of a law suit. The fact that the MOU is not a contract actually protects the researcher from possible legal claims by participants in a research project. From the standpoint of an individual participant or an Aboriginal community wanting clarity and shared understanding of the nature of the project and the obligations, it may be important to consider whether an MOU is sufficient or whether a contract with the researcher is more appropriate. If the research involves Aboriginal jurisdiction, cultural property or values, then participants may want accountability, want to review the data or the report before publication, and if they want co-ownership of the data and analysis, those should be addressed in a contract. Recalling the earlier discussion of ownership, control, access, possession, transparency and accountability, the current ethical guidelines give very limited, if any, legal protection on these issues. Contracts between researchers and subjects can be important to clarify mutual expectations and responsibilities.

Caution must be exercised by graduate students who want to embark on community-based research and share OCAP with the community. Universities regulate ownership of theses and dissertations, which regulations may not be amenable to sharing copyright. More fundamentally, however, to give a community control over data and/or analysis of a thesis or dissertation opens the researcher to the possibility the community will reject the data or the analysis. Doug Durst, with the University of Regina, astutely warns his students that such projects might “not [be] possible”:

It is true that the student can complete his research using the principles of participatory research but giving up ownership and control is self-defeating. First, the student may become committed to a research project that is not his/her interest. It may not be “do-able” in a reasonable time frame and it may not be applying sound research methods. Finally, I add, “What will you do if the community tells you that you cannot print the findings?” (2004, p. 11)

For our purposes, the crucial question in this situation is what are the respective legal rights and obligations of researcher and community when the community rejects the data or analysis. If the research agreement was actually an MOU – that is, if by its express or implied terms both parties intended not to create binding legal obligations – then the researcher has the right to publish and disseminate the research. This may not be ethical and it will undermine the researcher’s relationship with the community members, but publication will not open the researcher to a claim for breach of contract.

If, however, the community had an agreement with the researcher, then the publication rights will be governed by the terms of the contract. If the contract gives the community the right to share control over results, and the researcher publishes the findings and attends conferences sharing the results despite the community’s instruction otherwise, the community or its representatives may sue the researcher for breach of contract. If they succeed, the court may award compensation to the community proportionate to the economic damage or physical injury caused by the publication. As well, the court may order the researcher to cease any further publication of the research. As in many litigation matters, the damages will provide consolation, but they cannot begin to repair the public misinformation, or the humiliation caused by the breach of contract. In addition to legal safeguards, the researcher’s commitment to his/her relationship with the community is a critical safeguard for the community.

Another aspect of researcher liability originates in the funding agreements. Durst (2004) recorded his experience in dealing with funding administrators in a project where a First Nations agency shared control over the data. In the application for funding of the project, Durst explained the co-ownership agreement and the federal government agreed to fund the project. Although he hoped Memorial University would administer the funds, the research office had difficulty with the co-ownership aspect of the project. In the end, the First Nation administered the grant. (2004 at p. 11)

Thus, where originally the community’s role related to participation and control over the research, eventually the First Nation also took on the role of administering the research funds. Did this give rise to any contractual liability? The answer depends on the terms of the funding agreement. If the funding agreement stipulated the research monies had to be administered by a university, then there was a technical breach of contract. Then the issue is what damages flowed from the broken contract. As long as the First Nation administered within the terms of the funding agreement, then the damages were either minimal or non-existent. So even though one party did not comply with the contract, there is no point in suing because there were no damages.

In summary, contractual obligations arise between researchers and participants when they have agreed to certain terms, and they intend those terms to be legally binding. *Matters of ownership, control, access and possession ought not to be dealt with informally in a memorandum of understanding. To clarify the mutual understanding of these points, and to protect a community’s vital interests, such important property issues ought to be set out in a written contract.* Only contracts can be enforced by courts.

## 9.2 Liability for Negligence

A person may bring an action for negligence where a researcher owed a duty of care to the person and failed to fulfill that legal duty, thereby causing economic damage or physical injury. The most typical instance of negligence liability is for failure to obtain informed consent.<sup>9</sup> The doctrine of informed consent exists to protect every person's right to physical and emotional integrity.

In *Hopp v. Lepp*,<sup>10</sup> the Supreme Court endorsed the following statement of the Saskatchewan Court of Appeal regarding the scope of a physician's duty to provide information when obtaining consent to treatment:

In ordinary medical practice the consent given by a patient to a physician or surgeon, to be effective, must be an "informed" consent freely given. It is the duty of the physician to give a fair and reasonable explanation of the proposed treatment including the probable effect and any special or unusual risks.

...

One opinion is that the duty imposed upon those engaged in medical research, as were the appellants Wyant and Merriman, to those who offer themselves as subject for experimentation, as the respondent did here, is at least as great as, if not greater than, the duty owed by the ordinary physician or surgeon to his patient. There can be no exceptions to the ordinary requirements of disclosure in the case of research as there may well be in ordinary medical practice. The researcher does not have to balance the probable effect of lack of treatment against the risk involved in the treatment itself. The example of risks being properly hidden from a patient when it is important that he should not worry can have no application in the field of research. The subject of medical experimentation is entitled to a full and frank disclosure of all the facts, probabilities and opinions which a reasonable man might be expected to consider before giving his consent. The respondent necessarily had to rely upon the special skill, knowledge and experience of the appellants, who were, in my opinion, placed in the fiduciary position described by Lord Shaw of Dunfermline in *Nocton v. Lord Ashburton* ...

This passage clarifies that researchers owe fiduciary obligations as well as other legal duties discussed herein. The nature and scope of that fiduciary obligation will be addressed in the next section.

As part of obtaining informed consent, every researcher is obligated to disclose "material risks" to research participants, and what is "material" is to be determined with reference to a

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<sup>9</sup> Although it might seem that issues of improper consent might give rise to an action for battery, the Supreme Court of Canada has clarified that the proper claim against the researcher is in negligence. See *Reibl v. Hughes*, [1980] 2 S.C.R. 880 at 889.

<sup>10</sup> *Hopp v. Lepp*, [1980] 2 S.C.R. 192. ("*Hopp*").

“reasonable prudent person” in the participant’s position.<sup>11</sup> The Supreme Court of Canada has stated:

even if a certain risk is a mere possibility which ordinarily need not be disclosed, yet if its occurrence carries serious consequences, as for example, paralysis or even death, it should be regarded as a material risk requiring disclosure.<sup>12</sup>

What is a material risk is also a function of the participant’s circumstances – her age, income, marital status, “special considerations” and also depends on any specific questions the participant asked.<sup>13</sup>

How do these principles relate to research involving Aboriginal communities? *When a First Nation has research protocols in place, or by another means asserts jurisdiction or authority over research involving their lands or peoples, then this shapes the researcher’s obligations in obtaining free and informed consent. Similarly, where a participant asserts that the research project involves or risks an element of his or her Aboriginal culture or value, then a researcher must take this into account.*

A well-known example involves the Nuu-chah-nulth People, whose traditional lands lie along the west coast of Vancouver Island. A non-Indigenous researcher took tissue samples from several people in the community, used the tissue samples for purposes entirely unrelated to the reasons told to the community, and left tissue samples in storage on two continents upon his death. This will probably seem unproblematic to non-Indigenous researchers. Elaboration of cultural and spiritual contexts and meanings will show its offensiveness to Aboriginal people.

A growing consideration [in ethical research involving Indigenous populations] is the handling of specimens for future study, especially when genetic materials or permanent cell or tissue lines are established. For many Indian people, the removal of any specimen from an Indian is a metaphysical act; that is, a part of the “self” is removed. This little-discussed topic is operative more often than would be supposed. It is reminiscent of the earlier fear that one’s spirit was captured by photography. Despite widespread practice, the fundamental importance of this Indian point of view has not been controverted. As in so many aspects of Indian-ness, it isn’t always the act itself that is forbidden, but the manner in which the act is carried out. That is, Indians may often feel more agreeable to the storage and disposition of specimens if this is carried out with appropriate respect and seriousness of purpose. The principle reflected in the concern of Indian people about the repatriation of human remains and cultural items also applies to considerations of the collection, storage, use and ultimate disposal of all tissues and samples. (Rhoades, 2000 at p.427)

Accordingly, protocols, values, and norms about treatment and disposition of tissue samples may have sufficient significance to an Aboriginal research participant to render those protocols or norms to be integral to giving of informed consent and conditions of participation in the research.

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<sup>11</sup> *Reibl*, supra at 16.

<sup>12</sup> *Ibid.*, *Hopp* at p. 210.

<sup>13</sup> *Arndt v. Smith*, [1997] 2 S.C.R. 539 at para 9.

### 9.3 Liability for Malpractice

Malpractice involves failure to meet the standard of competence of the researcher's profession. *Doctors, social workers, psychologists will all be held to the standard of a competent researcher in that field.* Actions may be brought in civil court or complaints may be filed with boards regulating professional conduct.

### 9.4 Liability for Assault and Battery

Separate and apart from criminal liability for assault, a participant could sue a researcher for assault and battery to recover financial damages for any loss or injury. Civil assault and criminal assault have different elements and different burdens of proof. This discussion will consist of a brief overview of the civil law of assault and battery. Civil assault and battery are defined as, "causing another person to apprehend the infliction of immediate harmful or offensive force on her person coupled with the actual infliction of that harmful or offensive force".<sup>14</sup> In these torts, intent to assault is irrelevant. Wherever the researcher intended contact, and physically touched the other, then she is responsible for any ensuing physical or economic damages. The law becomes more complex because express or implied consent is a defence to battery. However, consent obtained through duress, misrepresentation, exploitation, or fraud is not genuine consent and will not be treated as such. Further, where the parties had drastically unequal power that the participant could not freely choose, then the consent will not have legal effect.<sup>15</sup>

*These dynamics may come into play in research involving Aboriginal communities or people where extreme poverty may motivate people to participate in research projects and risk their well-being for a small fee. Unlike the other categories of liability discussed above, a person can sue for battery without proof of damages.*

### 9.5 Liability for Breach of Fiduciary Duty

Fiduciary obligation arises where one party, in this context, a researcher, has discretion to make a decision that affects the beneficiary/participant's legal or practical interests, and where the beneficiary is peculiarly vulnerable to the fiduciary holding the power. The relationship between physicians and patients has long been identified as a fiduciary relationship.<sup>16</sup> As a consequence of this power and vulnerability, the law requires the fiduciary to act in good faith, be loyal, avoid conflict of interest and self-interest. In an earlier quote from a decision of the Saskatchewan Court of Appeal in *Halushka*, that court found *researchers owe at least as weighty a fiduciary duty to research participants as physicians owe to patients.*

In addition to the numerous professional interests of the researcher influencing research agendas and day-to-day decisions by researchers, research is becoming increasingly commercialized, particularly in biotechnology. Cote assembled the following statistics:

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<sup>14</sup> *M.(K.) v. M.(H.)*, [1992] 3 S.C.R. 6 at para 17.

<sup>15</sup> *Norberg v. Wynrib*, [1992] 2 S.C.R. 226 at para 26.

<sup>16</sup> *Supra* at para 64.

In [a] recent survey of Canadian academic-industry relationships, the amount of research funded by for-profit corporations rose from 2% in 1976 to 12% in 1996. As well, the pharmaceutical industry's funding of research rose from 15% in the 1980s to over 30% in 1996, while 29% of health research was performed in a private setting, up from 9% in 1976. By 1999, the pharmaceutical industry spent \$19 billion on research and development compared to Canada's Medical Research Council, now the Canadian Institutes of Health Research, which spent only \$19 million. The genetic research enterprise is by no means untouched by this trend. Commentators point tellingly to the fact that "[n]early every major geneticist is associated with a biotechnology firm; some as directors, others as consultants. And scientists, hospitals, and universities are patenting genes." Gene therapy sales are expected by some to reach \$3.5 billion by 2005.(references omitted) (Cote, 2002 at para 3)

These commercial interests place the researcher in a precarious zone – given the nature of their projects they cannot avoid having interests other than the participants' well-being. The question then arises, how does the fiduciary dimension of the relationship shape the researcher's obligations to participants? Given the vulnerability of the participant and the competing professional and financial interests of the researcher, it follows that at a minimum the researcher ought to disclose the nature of their financial benefits from the research enterprise. From the perspective of the participant whose informed consent is necessary, particularly in a First Nations community, disclosure of financial interests of the researcher and disclosure of the purpose of the research more generally are both critical pieces of information.

Article 22 of the TCPS supports the view that this disclosure is necessary:

In any research on human beings, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail.

Currently, Canadian law does not define the precise scope of the fiduciary relationship a researcher owes to participants. However, in research involving Aboriginal communities, collective interests emerge in addition to the interests of individual participants, and disclosure or transparency have greater importance. When the community gives the researcher access to traditional knowledge, private cultural practices, personal experiences, or tissue samples, the community places itself in a vulnerable position relative to the researcher and any institution backing the research.

*The primary means for a community to have some measure of control is to create a strong research contract with the researcher, setting out the process and the rights and obligations of each to the other. Even with such an agreement in place, an Indigenous community may be vulnerable to the researcher misusing the data or the analysis. Where a fiduciary obligation exists, courts are vigilant in protecting the interests of the beneficiaries – participants in this context – and research policy can soundly reinforce these values.*

## 9.6 Insurance and Liability Issues in Community-based Research

Canadian universities have collectively created an insurance program that insures universities and all research projects that involve one person affiliated with a university as long as that person has a principal role in the project.<sup>17</sup> Universities perceive that as long as one of the principal researchers is an employee of the university or has some less formal relationship with the university, that the university can exercise some degree of control over the project in terms of identifying legal risks and managing those risks. Typically, funds will flow through a university research account, and the university will ensure the funds are spent in compliance with the funding agreements for the research project.

For First Nations and Aboriginal communities who want full control over research projects without university oversight, those projects are not covered by the universities' insurance policies. As such, communities and researchers must understand their respective risks associated with various types of research and their options with regard to insurance.

Where community-based research is not affiliated with a university, several important legal issues must be addressed. First, as mentioned elsewhere, the university's insurance policy will not cover the project or the researcher. Consequently, the community and the researcher should consider the extent of risk, that is, the probable magnitude of damages. Obviously, medical research has a higher risk than social science research. But in any case, the researcher should seek insurance from a private insurance company to cover the project and any possible injury to a participant. The community, the researcher, and the participants may each have distinct interests. So although one party may conclude insurance is unnecessary, all should thoroughly consider the issue. From a participant's perspective and a community's perspective, it may be advisable that persons proposing to conduct research provide proof of insurance. In university-affiliated research, any injured person could claim against the researcher and the university. However, in community-based research, there may be no one with enough money to adequately compensate the person or group for their injury. Insurance is an important consideration from every perspective.

Another issue arises for community-based research, because such projects typically do not have the ability to seek approval by a university ethics review board. For example, currently in northern Saskatchewan, the University of Saskatchewan ethics review board is the only such board. It considers research proposals by all university-affiliated researchers as well as all physicians regardless of whether they have any affiliation with the university. However, for its own liability protection, the University research ethics board resists considering ethics of non-university research proposals. Indigenous organizations or governments may create a research ethics board. However, external, non-Indigenous funders and insurers may be reluctant to get involved in projects wholly based in communities.

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<sup>17</sup> Limited information about the Canadian University Reciprocal Insurance Exchange (CURIE) can be obtained from their website at <http://www.curie.org>. This section of the paper is based on conversations with Keith Shakespeare, Chief Operating Officer and Attorney in Fact at CURIE on February 18, 2005, and with Bruce Waygood, the University of Saskatchewan Coordinator for Health Research on November 17, 2004.

*Given these challenges, it may be prudent for community-based researchers to approach insurers and funders to discuss and perhaps negotiate what kinds of projects would be covered or funded under the alternate ethics review system.*

## **9.7 Summary**

This section has explained the most typical kinds of legal claims made by research participants against researchers. Anyone who is deciding whether to take legal action should not rely on this information, which is for informational purposes only.

Indigenous communities can use contracts to create legally binding agreements with researchers. These agreements can address process and protocol issues, research hypothesis, parameters of data collection, analysis, publication and other dissemination of results. In addition to providing legal protections to the parties, such agreements have value because they require the researcher and community to sit down and talk about the various ways things can go wrong, and how to meet their interests in those circumstances. These difficult conversations build relationships. Whether or not a contract is in place between researcher and participant, the laws of fiduciary obligation and negligence protect participants and communities from misusing their power and for improper conduct.

Within the law of negligence, informed consent is a process rather than a document. As a consequence, a researcher can obtain a signed consent form then by his own conduct nullify the consent and open himself to liability in negligence. Courts judge sufficiency of the ongoing disclosure of information to participants, in part, based on the culture of the participant, among other factors. Researchers in Indigenous communities or working with Aboriginal participants may inadvertently void consent by a participant, if the researcher fails to attend to cultural differences and norms.

First Nations are sovereign, a First Nation's jurisdiction extends over its traditional lands and people, in the same way Canada's jurisdiction applies to its lands and people. Funding institutions, universities and research ethics boards cannot ignore the claim by an Indigenous community to jurisdiction. These institutions must adopt practices and ethical standards which require researchers to determine the local protocols and practices. Regardless of whether the protocols are published on the internet or, in the other extreme, carried by traditional knowledge carriers, the standards exist and must be respected. The assertion of jurisdiction triggers an obligation to consult and accommodate. The Honour of the Crown demands no less. By implementing standards that incorporate local Indigenous protocols into research ethical norms, the PRE will be taking every measure it can to ensure the era of exploitative research in Indigenous communities is over.

## **10.0 Recommendations**

While it is true that research has brought many benefits to human society, it has also been a negative experience for many Indigenous communities. How research that involves Indigenous Peoples will take shape into the future will depend primarily on the degree of assertion Indigenous Peoples make about their knowledge systems and how accountable they hold the whole of the

research enterprise to the practice of ethics. How Indigenous Peoples assert their knowledge and what kind of knowledge will be released from communities to the outside world needs to be understood within perimeters of benefiting Indigenous communities and the protection of cultural and intellectual property from needless exploitation. As Indigenous Peoples' research advances, the more critical it will become and perhaps more recognized for its value in transforming knowledge. However, this tactic alone will not be the legacy that imprints Indigenous research into the ethical history books. Rather, it is how far Indigenous Peoples' research can liberate thought and make the transformations urgent enough for people to want to carry them out and difficult enough to carry out for them to be profoundly rooted to reality that will make the difference (Ermine, Sinclair & Jeffery, 2004). Apart from this quest, which the Western institutions must undertake in cooperation with Indigenous Peoples, there is no reason why Western research should continue to infringe on Indigenous Peoples' spaces.

- To protect the heritage of a sacred body of knowledge, Indigenous Peoples, and in particular the Elders and knowledge keepers of each community, must be informed and exercise control over all research that relates to heritage within their territories.
- The Granting Agencies should explicitly recognize the rights and privileges of alternate knowledge systems represented by Indigenous Peoples. This recognition should include the support and development of educational, research and training centres which are controlled by indigenous communities, and strengthen these communities' capacity to document, protect, teach and apply all aspects of their heritage.
- Governments, research institutions, and Research Ethics Boards should discourage institutional based research regarding any element of Indigenous Peoples heritage without the explicit approval and guidance of Indigenous authorities, Indigenous Elders and knowledge keepers.
- In the event of a dispute over the custody or use of any element of an Indigenous Peoples' heritage, judicial and administrative bodies should be guided by the advise of Indigenous Elders who are recognized by the indigenous communities or peoples concerned in having specific knowledge of traditional laws.
- Researchers must not publish information regarding any information or knowledge obtained from Indigenous peoples or the results of research conducted on flora, fauna, microbes or materials discovered through the assistance of Indigenous Peoples.
- The jurisdiction of Indigenous Peoples over their culture, heritage, knowledge, and political and intellectual domains must be explicitly recognized in the Tri-Council Policy Statement and in review documents and proposals currently being developed.
- In recognition of Indigenous jurisdiction, research agreements need to be negotiated and formalized with authorities of various Indigenous jurisdictions before any research is conducted with their people. Concepts of OCAP; ownership, control, access, and

possession of all data and information obtained from research involving Indigenous Peoples, must become normative standards. For example, two critical issues are:

- Negotiations on “benefit sharing” and “benefit sharing agreements” in Genetic research must not take place in advance of genuine Indigenous community consultation and consent.
- Genetic and biological research must cease until Indigenous authorities have articulated specific direction on these issues Elders, leaders and communities.
- Indigenous community empowerment and benefits must become central features of any research entertained and conducted with respect to Indigenous Peoples. Professional associations of scientists, engineers and scholars, in collaboration with Indigenous Peoples, should sponsor seminars and disseminate publications to promote ethical conduct in conformity with these guidelines and develop processes and structures to discipline members who act in contravention.
- Understanding Indigenous worldviews, social structures and systems, and the role of education and pedagogical forms in the process of knowledge and cultural transmission, is a vital necessity in coming to terms with research involving Indigenous Peoples. Education in these respects must be supported with appropriate funding and resources.
- Steps must be taken to immediately implement policy that will ameliorate inherent conflicts between Research Ethics Board policies and Indigenous ethical requirements, the primary example being the barriers to meaningful negotiation of consent and research parameters on the part of community participants prior to the receipt of formal approval from institutional Research Ethics Boards.
- Further conceptual development of the ethical space will require guideline principles put into effect by the three granting agencies that cement practices of dialogue, negotiation, and research agreements with Indigenous authorities in any research involving Indigenous Peoples.
- Ongoing efforts by scholars and political groups to formulate the parameters of national copyright laws and the protection of Indigenous Peoples’ intellectual and cultural property rights must take extreme urgency. Protection and recognition of Indigenous peoples’ intellectual and cultural property rights by researchers and institutions must be part and parcel of any funding received from the three granting agencies.

## **11.0 Conclusion**

Bringing together perspectives that are clearly illustrative of divergent worldviews; namely, Indigenous dialogues of the Elders and legal discussions pertaining to research, in one report initially seemed awkward. However, we found that, ironically, there is a comfortable fit between the assertions of the Elders and the protections and cautions that might be afforded in law with respect to research practices based upon Indigenous frameworks. We most certainly determined that there are bases in law to make powerful assertions of the right to develop culturally relevant

and appropriate frameworks and processes in research. We make these assertions as part of a collective Indigenous effort to respectfully draw attention to the point that Indigenous people are more than willing to dialogue and participate in meaningful exercises that will lead to shifts in the research paradigms that will be claimed by all as ethical.

We come to the discourse with some cautions, recognizing the persistent form of divergence, an alienating tension, at times bordering on animosity, that tarnishes and hangs like a dark cloud over the on-going association between Indigenous Peoples and the Western world. It is a time-lagged issue because the protracted matter of division had its genesis so long ago and the ensuing time span of relations has not alleviated the condition to any perceptible degree of comfort on either side. From the Indigenous perspective, the term mistrust is emphasized because the course of Western colonialism following contact, with its trail of misconceptions, deception, domination and even violence, has left distinct and sour imprints in the minds of many Indigenous Peoples about the possibility of forging any trustful relationships with the Western world. Similar disengagement exists in how the West seems unwilling to understand the overarching paradigm for advancing total human knowledge (Ermine, Sinclair & Jeffery, 2004).

The notion of a knowledge tradition, complete with its luggage of beliefs, context, and processes imposing into another knowledge domain, ad hoc, elicits something improper. As we have stated, this matter of cross over into different jurisdictions and cultures requires, at the least, a protracted process of dialogue for it to be even considered. In essence, dialogue must become a central feature of a new relationship between Indigenous Peoples and other traditions of knowledge. The ethical space between cultures offers itself as the theatre for cross-cultural dialogue for the objective of ethically engaging different knowledge systems. According to Bohm (1996), dialogue enables inquiry into processes that can fragment and interfere with real communication between individuals, nations, and even different parts of the same organization. Dialogue is concerned with providing a space for exploring the field of thought and attention is given to understanding how thought functions in governing our cross-cultural behaviors. It is a way of observing, collectively, how hidden values and intentions can control our behavior, and how unnoticed cultural differences can clash without our realizing what is occurring. Dialogue is essentially a 'conversation' between equals. Cross cultural research has been problematic because of this neglect for the unseen, unstated influential undercurrent of hidden values and intentions.

The purpose of this report has been to contribute to the burgeoning Indigenous research discourse that encompasses Indigenous epistemology as the theoretical foundation, Indigenous protocols and practices as methodologies, and the right of Indigenous communities to develop their own knowledge centers. The Elders remind us of the Indigenous community and the living and sacred knowledge that passionately orients the people as the future is negotiated. This knowledge is a sacred trust given in perpetuity to the people that embrace it and as a trust, must not be compromised. The Elders remind us of the standard of ethics and honor that are inherent in the Indigenous value system that should now inform the unfolding new age of respectful cross cultural interaction. History shows that the various structures of knowledge production and the rules of practice in dominant knowledge institutions are not adequate to be given the responsibility for the continuity of Indigenous knowledge. Governments and research institutions and their representatives now have a duty to consult with Indigenous Peoples and must at all times bring honor to the crown.

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