EXPLORING KEY STAKEHOLDER PERSPECTIVES FOR A COLLABORATIVE

FIRST NATION RESEARCH PROTOCOL

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ABSTRACT

EXPLORING KEY STAKEHOLDER PERSPECTIVES FOR A COLLABORATIVE FIRST NATION RESEARCH PROTOCOL

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This thesis proposes a set of recommendations to assist the Keewaytinook Okimakanak Research Institute (KORI) in developing codes of conduct of research with the First Nation. It places the discussion of research ethics in the context of cultural world view and the struggle for self-determination as peoples and nations. It affirms that the First Nation Peoples have a right to participate as partners in research that generates knowledge affecting their culture, identity and well-being. To provide the context and rational for the recommendations presented, the thesis outlines how ethics are framed in the First Nation with respect to research design, informed consent, entry into the field, confidentiality, approaches to data collection, participant roles, ownership of data and dissemination of results. The thesis also describes how First Nation perceptions of reality and ethical behavior contrast with the norms prevailing in western research. The perspective of community ethics suggests that representation of multiple voices, enhancement of moral discernment, building capacity, empowerment, and self-advocacy need to be critical components of research. This study emphasizes that the research process needs to be reciprocal and collaborative, with communities, researchers, research organizations, academic institutions, research councils and funding agencies working together to shape the conception, definition   and   direction   of   research   in   the   North.

Acknowledgements

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List of Abbreviations

CBR	Community-Based Researcher
CC	Community Contact
CIHR	Canadian Institute of Health Research
CURA	Community-University Research Alliance
FNIHB	First Nations and Inuit Health Branch of Health Canada
IAPH	Institute of Aboriginal Peoples' Health
KORI	Keewaytinook Okimakanak Research Institute
NAHO	National Aboriginal Health Organization
NSERC	Natural Sciences and Engineering Research Council
NZNO	New Zealand Nurses Organization
OCAP	Ownership, Control, Access and Possession
PAR	Participatory Action Research
REB	Research Ethics Board
SSHRC	Social Sciences and Humanities Research Council
TCPS	Tri-Council Policy Statement
WHO	World Health Organization

Chapter One: Introduction

Context

The First Nations people, predominantly since the reserve systems were established and federal services implemented (in these reserve areas), have been 'subjects' for a myriad of researchers, investigators, government officials, consultants and academics (O'Neil, 1998). The argument put forward by the outsiders is that documentation is needed to determine required levels of health and other services, to evaluate whether programs are effective in accomplishing their goals, to assist communities in accessing resources available in government programs as well as for planning purposes. The First Nations people do recognize that some research has been beneficial and essential to their communities but flawed ethics in research practices have overshadowed potential benefits (Browne *et al.*, 2000; Smylie 2000). The general consensus among First Nations people has been that data collection has been one-sided; that investigators enter communities for motives of personal career enhancement, academic publishing or financial incentives rather than truly addressing concerns of the First Nations people. The First Nations people often feel that research has been initiated outside of the community and that non-Aboriginal personnel facilitate this research without appropriate consultation. A researcher usually enters a community for a short-term stay, extracts information and biological samples, and then leaves the community without clearing the results to later publish their own conclusions without the community's consent, knowledge or verification (O'Neil, 1998). Research activities conducted in this manner may be inaccurate and offensive as there is no cultural context on which to base conclusions and researchers likely do not use culturally sensitive methods to collect data or recognize the importance of oral traditions. Researchers may also indiscriminately publish information with no regard to the effects on the community it came

from, and leave the community without helping to develop capacity among community members in research protocols or analysis. Resulting reports may publish erroneous conclusions that do not have the benefit of a community's analysis and input (Kerln, 1996). Thus, First Nation communities have had almost no opportunity to express their desires or concerns about the topic of research nor have they been provided with the opportunity to correct misinformation.

As a result, resistance to the oppressive effects of research driven by external agendas is emerging in the First Nations (O'Neil, 1998). The First Nations people communities are increasingly demanding that all phases of research including design, implementation, analysis and interpretation, be vetted through appropriate First Nations authorities. Furthermore, they would like to see all research activities to provide significant opportunities for First Nations capacity building (NAHO, 2002).

It should be noted that professional institutions have begun to redesign their codes of ethics in research in response to the particular needs of First Nations communities. A good example is the "Code of Conduct for Research Involving Humans" developed by the Tri-Council Working Group in 1996 (Medical Research Council et al., 1998). While these codes acknowledge that ethical and culturally sensitive principles must be adapted, this is offered as more of an observation than a prelude to instruction about the manner in which to achieve this adaptation. Without direction, these codes are left to the individual interpretations of Research Ethics Boards (REB) and researchers; and the interpretation of such will most likely result in research that is one-sided and not of benefit to the First Nations people.

Some of the research areas in particular are becoming complex with the emergence of biotechnology, biomedicine and funding by private corporations. The ethics of research involving First Nation communities needs to be defined within a framework that allows for

cultural relevance and sensitivity as well as an ongoing process of communication and negotiation between the communities and their respective researchers.

Health Research in a First Nation Context

The Meaning of Health

The World Health Organization (WHO) definition of health is based on a broad view encompassing mental, social, spiritual and physical components, as depicted by the sacred medicine wheel of the Aboriginal people. Since the proclamation of the Ottawa Charter for Health Promotion (1986) our understanding of holistic health has improved (MacMillan *et al.*, 1996). The growing field of health promotion has generated a wealth of knowledge about how to improve individual, community and population health in the broadest terms. The Ottawa charter speaks of health promotion as the process of enabling people to have control over their health through building health public policy, strengthening community action, developing personal skills, creating healthy environments and reorienting health services. Such strategies have proven helpful to policy makers and community developers around the world as they strive to improve the health of and well-being of their people. Health promotion is centrally concerned with equity, participation and empowerment. Vulnerable populations and individuals are given priority, but none are excluded from a concern and an understanding of health and well-being.

Health Status

The degree of ill health in the Aboriginal population is one of Canada's major unresolved issues. Although there have been significant improvements over the past few decades, the overall health

status of Aboriginal peoples is well below that of the others living in Canada. Mortality and morbidity records indicate that:

- Life expectancy, while varying among communities, remains significantly less than that of the average Canadian

- The incidence and prevalence of chronic and degenerative disease (diabetes, cardiovascular disease, cancer and arthritis) is increasing

- Injuries and poisoning have an unacceptably high impact on mortality and morbidity among Aboriginal peoples

- Certain infectious diseases remain prevalent (sexually transmitted diseases, hepatitis, shigellosis, tuberculosis and meningitis). New diseases such as HIV may have a devastating impact

- Gastrointestinal, respiratory, ear and skin infections are frequent in most remote communities

- Manifestations of acculturation stress and mental health problems (such as violence, suicide and sexual abuse) are widespread

- There is a high burden of diseases resulting from abuse of tobacco, alcohol and other substances, poor nutrition, obesity and physical inactivity (MacMillan *et al.*, 1996)

The Nature of the Challenge

The health status of Canada's Aboriginal peoples is a result of a myriad of factors: social, biological, economic, political, educational and environmental. The complexity and interconnectedness of these health determinants suggest that the health status of Aboriginal peoples is unlikely to improve significantly by increasing the quantity of health services alone (MacMillan *et al.*, 1996).

The research process that has been supported by academic institutions, research councils and federal agencies has been limited in its ability to address the disparate health issues; the problem being that Western scientific inquiry often conflicts with traditional Aboriginal views of cause and effect, and paradigms of knowledge. The application of mono-cultural and/or scientific

methodology may be regarded as insensitive and as a result, ignored by communities. The information that is produced from such research may not be valued and will be rejected by communities. More significantly, a lack of understanding of differences in cultural paradigms may result in misinformation and inaccurate data. What is required is research that is undertaken in a cross-cultural context. There is a need to account for Aboriginal cultural and operational paradigms about science, acquisition of knowledge, processing knowledge, time, individual verses collective priorities, and how the world works.

Problem Statement

Increasingly, First Nations peoples and community-based organizations are articulating a need for formal guidelines for conducting ethical and culturally sensitive research. This is part of an initiative led primarily by Northern Ontario scholars to advance new ethics for the conduct of research involving First Nations people (Castellano, 2004). For example, the National Aboriginal Health Organization, representing First Nations, Métis and Inuit people of Canada is advocating four criteria for research involving Indigenous people: ownership, control, access, and possession at the community level (Schnarch, 2004). Principles such as these raise new ethical concerns, for example, how to protect confidentiality when data is retained by a community. They also raise practical concerns, for example, the additional time, resources and know-how needed in order to build relationships and negotiate community-level agreements during a project, and the uncertainty about whether the researcher can disseminate results after a project is completed. So far, there has been no unified statement or consensus on an Aboriginal research protocol to address this matter. An effective research protocol can only be developed through mutual collaboration among stakeholders. Thus, there is a current need to stimulate

broad local and national debate between stakeholders, and to bring more Aboriginal groups and perspectives into the discussion of research ethics so that true partnerships between researchers and communities can be achieved. A true research partnership is one that is based on a mutually beneficial arrangement entered into for the purpose of accomplishing mutually agreed upon objectives. It is upon this principle that the Keewaytinook Okimakanak Research Institute (KORI) has designed its Community Consultation Guidelines for conducting ethical and culturally-appropriate research in the First Nations.

Significance of Research

A research protocol that is based on mutual collaboration between the First Nations people and researchers has a number of very practical benefits in addition to the political importance:

a) It provides a holistic perspective

b) May contribute to self-determination and healing activities of communities and may be a catalyst to community empowerment

c) It allows a participatory approach to research, which means that people are involved in research, not just as subjects but as collaborative partners throughout the entire research process – hence it has a capacity development dimension

d) The data collection has a higher probability of being useful for community policy making as it has been developed and driven by community priorities

e) Data collection is likely to be more accurate as communities and organizations perceive that the time invested to collaborate is worthwhile in terms of benefits to their planning and programming activities

f) It allows training and development of First Nations people and contributes to economic development

g) It ensures that the analysis is not biased by non-Aboriginal values and beliefs which may be unconsciously held by external researchers

Research Goals and Objectives

The goal of this study is to identify key stakeholder perspectives about the means and conditions

for research in partnership with First Nations communities. The following are the research

objectives that this study will address:

1. To document and analyze the perspectives of elders and leaders within First Nations communities on past and current research processes
2. To document and analyze the perspectives of community-based researchers (First Nations community guides for non-Aboriginal researchers) on the past and current research process
3. To document and analyze perspectives of non-Aboriginal researchers on the past and current research process
4. To analyze the appropriateness of the Keewaytinook Okimakanak Research Institute (KORI) Community Consultation Guidelines

Methodology

This study took place in the most northern community in Ontario, Fort Severn First Nation. The

data collection was divided into three segments, each of which corresponded to a stakeholder

group: elders and leaders, community based researchers and non-Aboriginal researchers.

Consistent with the oral traditions of the First Nation, the data collection for this study used

narrative as a method of inquiry and involved a combination of participant observation, one-on-

one interviews and sharing circles. The methodology was adjusted to fit under the requirements

of the KORI community consultation guidelines.

Organization of the Thesis

This thesis is organized into six chapters: Introduction, Literature Review, Methodology,

Findings, Discussion, and Recommendations and Conclusions.

Eight topics are examined in the Literature Review: The Nature of Traditional Aboriginal

Medicine and Health; The Differences between Traditional Aboriginal Medicine and Western

Medicine; Conflicts of Integration with Aboriginal Traditional Medicine and Western Medicine;

Understanding the Contextual Issues: Aboriginal Health and Well-being; Strategies for Health

Research, Programs and Services; Key Competencies for Consultants, Researchers and

Professionals in Aboriginal Environment; Components of the Health Care System; and Positive

Health Outcomes. Health and medicine is indicative of a key area where Aboriginal

communities get bombarded with outside consultants, researchers and professionals because it is

a sector that lags behind mainstream Canadian standards. However, the conceptual framework

can be modified and applied to any area of research in Aboriginal communities.

The Methodology chapter is organized into six sections. The first section describes the

context of the research with respect to the Fort Severn Community, the Keewaytinook

Okimakanak Research Institute (KORI) and the University of Guelph. The second section

discusses the shift in methodology required to adhere to the KORI Community Consultation

Guidelines. The third section defines the constituents of each stakeholder group (elders/leaders,

community-based researchers and researchers). The fourth section provides methodological

background for the study. This includes an overview of oral traditions in First Nations culture

followed by a discussion of narratives as an appropriate method of inquiry. The fifth section

outlines the data collection process. The sixth section discusses the trustworthiness of the data

collected, the procedures used for data analysis and the emerging themes that resulted from the analysis.

The Findings chapter reports the data collected from participant observation, one-on-interviews and sharing circles. The Discussion chapter examines the themes that that were emergent from the literature and the findings. Eight themes are identified as a factor in developing a collaborative research process in the North: Research Councils and Funding Agencies; Community contact and intermediaries; Power and consent; Ownership; Positive Outcomes; Building relationships; Research methods; and Participation. The chapter concludes with a discussion of OCAP which connects the themes from the literature and the findings.

In the *final chapter,* I present recommendations for First Nations communities, non-First Nations researchers, funding agencies, intermediary organizations and research ethics boards on designing and implementing a research project. The recommendations are presented in eight headings: Entry; Negotiating research; Benefits of Research; Consent; Confidentiality; Ownership and publication of data; Investment of time and funding; and Intermediary organizations. A summary of the recommendations is provided as well as concluding remarks with the implications for conducting collaborative research in the future.

Key Conclusions

Research in the First Nation should be an on-going collaborative consultative process that involves the institution, the community and the individuals at every stage so that mutually agreeable research goals can be reached.

The community's potential need for debriefing should be considered by researchers and organizations. Procedures should be outlined in a research agreement with communities in the

form of a written contract. Issues pertaining to consent, confidentiality, partnership roles, ownership and publication should be included in the discussion and agreement of research goals.

Funding agencies need to include sufficient funding to allow ethical research according to the KORI Community Consultation Guidelines (e.g. community consultation, Aboriginal representation, reporting back to the community, provision of honoraria). Both funding agencies and research councils need extend timelines to reflect on the need for community consultations, recruitment of participants, training of researchers within the community and the multi-stage process of consent.

Chapter Two: Literature Review

With the introduction undergraduate rural and remote community-based medical placement programs, students are beginning to have the opportunity to work in partnership with Aboriginal communities and other health professionals and organizations, on measures to improve health of the Aboriginal peoples. A key role for these future medical professionals will be to provide culturally relevant health care, integrating an understanding of local customs and practices into the promotion of health and the prevention, diagnosis and treatment of disease. Furthermore, consistent with the needs of Aboriginal peoples and local organizations, these undergraduate medical students should advocate for improvements to their health and social conditions, and in facilitating empowerment of individuals and communities to have ownership over their own health and health care delivery.

These medical students, as part of their placement, will work in collaboration with Aboriginal peoples and groups to promote a greater understanding and acceptance of their respective philosophies and approaches. This task, as highlighted in the following literature, calls for:

- An openness and respect for traditional medicine and traditional healing practices (e.g. sweat lodges, herbal medicine, healing circles). This should be balanced with a recognition that not all Aboriginal people, whether First Nation, Métis, Inuit, adhere to or understand their traditional ceremonial practices.

- Improved cross-cultural awareness in students, which could be facilitated by greater contact with local Aboriginal communities with whom they will be conducting their placements, and a better understanding of local Aboriginal cultures, history and current settings.

- Development of cross-cultural student-patient or student-community member communication skills.

- Addressing health concerns that are identified by the community (community agenda), through health prevention and promotion programs and workshops.

In order for the medical students to successfully bridge their skills with the needs of the Aboriginal communities, practice tools, resources, and health care delivery models must be developed to support them. Thus, the original proposed goal for this study was to identify the conditions necessary for developing community-driven[1] health programs, in the context of the undergraduate community-based medical placements. The proposed objectives were:

    i.   Identify community-driven approaches in adult education, health prevention and health promotion in Canada, as well as in comparable contexts such as the United States, New Zealand and Australia.

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[1]

Community-Driven

- Collective responsibility for community
- Community leadership
- Involvement of wide range of community members and community ownership
- Mutual relationships based on respect and trust
- Community determines the roles and relationships to the community
- Community determines resources to best meet needs
- Focus on support and fostering community leadership and shared responsibility for strengthening and sustaining community health and well being
- Joining community in its endeavors

(Ricks *et al,*. Page 78)

ii. Summarize and analyze the basic components or strategies of each approach.

iii. Explore existing health programs and ongoing prevention activities in each of the participating remote communities. The primary stakeholders would include: community health providers and administrators (health director, tele-health technicians, radiology technicians, mental health workers); the secondary ones would include selected patient groups.

iv. Document stakeholders' perspectives on strategies identified in objective (i) that could potentially complement or enhance existing health education and health care delivery in a community

v. Explore the implications of community-driven health programs as part of the undergraduate community-based medical placements in rural and remote communities

I approached one particular medical community and presented my research proposal. The concepts behind the proposed study were not received well. The general consensus was that a modified approach to administer medical treatment or education to Aboriginal communities was not needed. Therefore, in this literature review, I felt that it was important to compare and contrast Western and Traditional Aboriginal medicine to demonstrate the need for a modified, culturally-appropriate medical approach to community-based research and practice. Through the literature review, it became evident that it was important to first identify aspects of culturally respectful care that could ultimately be used to develop appropriate health care delivery systems and health professions educational programs for Aboriginal peoples. In fact, through the identification of these factors, an ethical protocol could be developed in order to guide practice and research with Aboriginal communities in any field. As a result, the goals and objectives for this study were revised to collect stakeholder (elders and leaders, community-based researchers,

and non-Aboriginal researchers) perspectives on how to conduct ethical and culturally-appropriate research in the North.

In accordance with the context, the eight topics reviewed in the literature were: Nature of Traditional Aboriginal Medicine and Health; Differences between Traditional Aboriginal Medicine and Western Medicine; Conflicts of Integration with Aboriginal Traditional Medicine and Western Medicine; Understanding the Contextual Issues: Aboriginal Health and Well-being; Strategies for Health Research, Programs and Services; Key Competencies for Consultants, Researchers and Professionals in Aboriginal Environment; Components of the Health Care System; and Positive Health Outcomes.

Although the examples in the literature focus on health and medicine, the conceptual framework presented at the end of the chapter can be modified and applied to other areas of research in Aboriginal communities.

The Nature of Traditional Aboriginal Medicine and Health

Traditional medicine is defined as those health practices and methods of care that are based on "Aboriginal health-illness beliefs and health care philosophy" (Shestowoski, 1993, p.6). The role that traditional medicine plays in Aboriginal society is demonstrated through the way in which traditional medicine provides for the expression and preservation of Aboriginal culture. For example, the medicine man is designated for the position through the consensus of the people. By adhering to the traditional norms in selecting medical practitioners through a consensus of the people, the dependant nature of traditional medicine on Aboriginal society is revealed (Shestowoski, 1993).

Through oral transmission, the knowledge and skills required to practice as a medicine man, is passed down from generation to generation. Oral communication is considered to be the only acceptable method of transmitting the knowledge system of traditional medicine. In practice, oral transmission of knowledge demonstrates the reliance that traditional medicine has on Aboriginal culture for its very existence, which in turn serves to preserve the culture of Aboriginal society (Shestowoski, 1993).

The reciprocal nature of the relationship between traditional medicine and Aboriginal culture is further shown by the realization that traditional medicine is "intricately tied into traditional Aboriginal philosophy, religion, and spirituality" (Shestowoski, 1993, pg. 6). A generalized description of the Aboriginal belief system, which includes traditional views of health and illness, is useful in articulating this relationship. Although much diversity exists within the Aboriginal population, the medical belief systems described in the global Aboriginal literature tend to exhibit similar attitudes, values, and behaviors with respect to health beliefs and practices. (Reid, 1983; Tynan, 1979; Shannon, 1974; Cawte, 1974; Taylor, 1977a; Taylor, 1977b; Waldock, 1984).

The North American Aboriginal health belief system is built around the Medicine Wheel (Figure 2.1 and Figure 2.2), which emphasizes the concept of balance and an approach to life that is holistic in nature.

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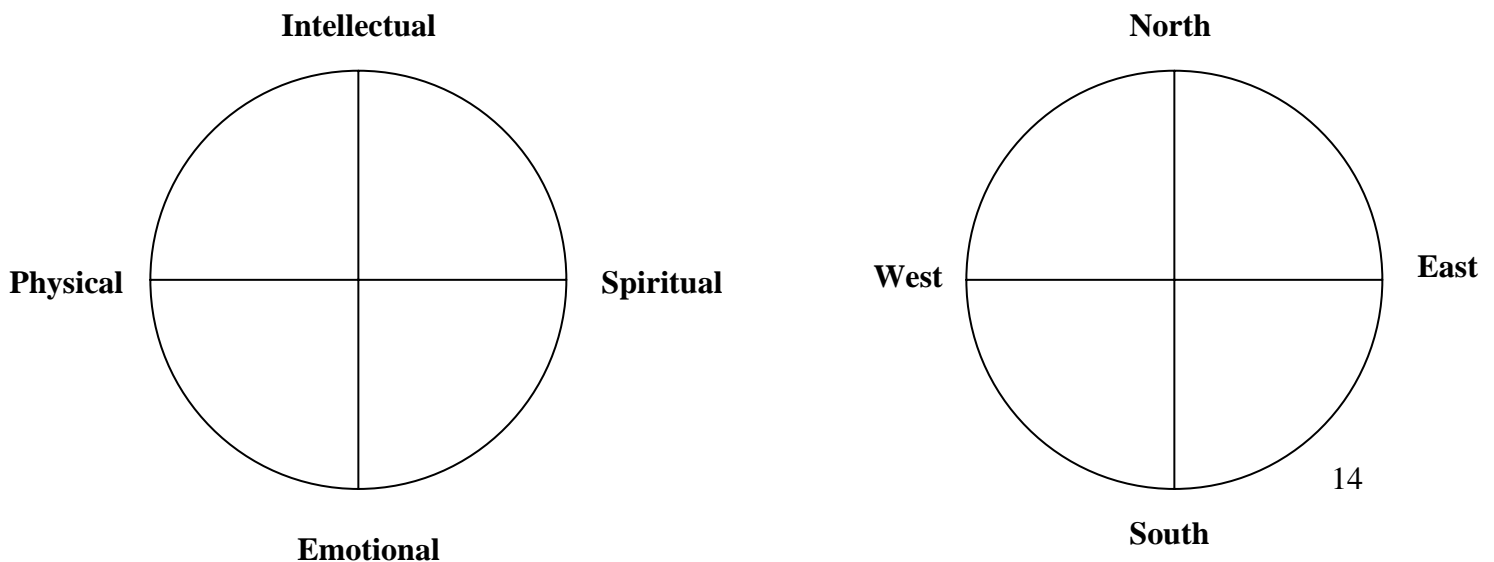
Central to this holistic approach is the assumption that balance is the ideal for which to strive, and that all activity, human and otherwise, is directed toward this goal. With respect to the self, the person is made up of four equal parts (the physical, the emotional, the mental, and the spiritual). Spirituality is that part of the self which believes in the connection of all things. Spirituality is having a sense of connectedness with all other creations of the Great Spirit. This connectedness allows for an inner awareness of the unity of all things, animate or inanimate. The related direction east is the direction for learning about sharing and love (Montour, 2000). Emotionality is that part of the self which can touch all other things through feeling. The emotional self can feel with trust and innocence, finding excitement in discovery and joy in the awareness that new knowledge brings. The related direction South is the direction for learning about honesty and trusting (Montour, 2000). Physicality is the part of the self, which recognizes and nurtures the body and the environment in relation to the cycle of life and death of all other things. The physical self is located on the West side of the circle. The West is the place for looking within the realm of the adult; and the direction for learning about respect, kindness, and activity that nurtures the self and others (Montour, 2000). Intellectuality is the part of the self, which seeks knowledge, understanding and wisdom. The intellectual self also requires that knowledge be put into action. Our intellectual self is located at the North of the circle. North is also the place of the elders and is the direction for learning about caring (Montour, 2000). Each of these four parts must be nourished in order to live a healthy, happy, and productive life. In addition to the desire for balance among these four components, is the belief that illness is not necessarily a 'bad thing', but instead a sign that is sent by the Creator in order to help people reevaluate their lives. Aboriginal culture takes the view that good health is a gift from the Creator that is to be respected through an appreciation of its value. The appreciation of a gift

from the Creator is expressed through rituals associated with Aboriginal spirituality, such as prayer, and the traditional smudge, or the burning of sweet grass. Inherent to the nature of Aboriginal spirituality, these religious practices also form the basis of illness treatments that are specific to Aboriginal medicine.

In addition to religion, the traditional health beliefs of Aboriginal people are also interconnected with many aspects of Aboriginal life such as the land, kinship and obligations (Tynan, 1979). The socio-medical system of health beliefs held by Aboriginal people places emphasis on the social and spiritual dysfunction causing illness. This approach underlines that "individual well-being is always contingent upon the effective discharge of obligations to society and the land itself" (Morgan *et al.*, 1997, p.598). Thus, individuals' social responsibilities and obligations may take precedence over their own health because of the priority given to social relationship in this model.

An alternate model divides people into four broad categories with regard to their health: (i) the strong – normal condition, able to cope mentally and physically with daily tasks, (ii) the weak – minor illness that requires rest and specific treatment for the condition (e.g. headaches, toothaches, etc); (iii) the wounded – have cuts, bruises and wounds from fights or accidents; and (iv) the sick – spiritual and supernatural influences that cause illness and can only be resolved with assistance (traditional healer) (Webber *et al.*,, 1975).

Both models view supernatural intervention as the main cause of serious illness. The belief in causation is divided into ultimate causes (e.g. breach of a taboo) and proximate causes (e.g. motor vehicle accident) of illness, injury or death (Reid, 1983; Peile, 1997; Johnson, 1978). These models provide a basis for the understanding of specific Aboriginal health beliefs and the differences between Aboriginal and Western models of health.

The integration of medical belief systems of Aboriginal peoples from multiple sources can be compiled within the framework used by Mobbs (1991) (Table 2.1). This framework is not meant to represent any definitive picture of beliefs in any particular Aboriginal community as there will be variation between and within communities, and these categories will alter with time. Rather, it illustrates, with specific examples, the way in which Aboriginal people have categorized illness (natural, environmental, direct supernatural, indirect supernatural and emergent or Western causes). These categories are not mutually exclusive, indeed there may be beliefs relating a single clinical entity to multiple possible causes (Cawte, 1984).

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Table 2.1: Framework Outlining Tradition Aboriginal Health Beliefs (Mobbs, 1991)

Categories of Illness Causation	Cause of Illness	Examples of resultant conditions
Natural (Part of everyday life, generally result in temporary states of weakness)	Emotions (resentment, sulking, shame, worry, homesickness, grief, jealousy, anger, anxiety) Dietary factors Physical assault and injury	Loss of appetite, weight loss, listlessness, pain, suicide or attempted suicide Diarrhea, coughs and lung complaints, headaches Physical injuries
Environmental	Winds The moon Climate-excessive heat and cold	Pain, stomach ache, diarrhea, chills Epilepsy or fitting in children Colds, aches, headache, respiratory complaints, diarrhea
Direct Supernatural (Transgression of the law)	Breach of taboos: Taboos of place-sacred sited Taboos of ritual ceremonies Taboos of pregnancy Taboos of relationship (parenthood, childhood, avoidance, incest, mortuary)	Multiple possible effects: Swelling, vomiting, diarrhea, drowsiness, madness, death, nausea, lethargy Difficult pregnancy, injured fetus, deformed child, skin sores, epilepsy, neck Pain with headache, leprosy, pneumonia, broken bones Weakness, vomit a lot and lose interest in living, influenza, sickness or death, madness
Indirect Supernatural Intervention (All illnesses attributed to sorcery is understood ultimately to be the result of social or religious offences, intergroup or intragroup conflict)	Boning, singing, painting	Multiple possible effects including: death, serious injury and illness, sterility, congenital defects,
Emergent/Western (Conditions only known by Aboriginal society since colonization)	Social and epidemiological changes which have occurred post colonization	Alcohol-related illness, substance abuse, spina bifida, cerebral palsy, diabetes, heart disease, cancer, sexually transmitted disease, smallpox, measles, bronchitis, influenza, diarrhea

Supernatural Intervention

Sorcery is the "central element in a theory that links illness and death to personal and social conflict or to the breach of ritual proscriptions" (Reid & Williams, 1984, p.127). Sorcery and supernatural intervention are part of the perceived reality of Aboriginal life. In society, explanations are often used to explain unfortunate circumstances (Waldock, 1984). For example, the deaths of infants, the very old, and the chronically ill are considered to be a normal event in a life cycle. However, death occurring outside of these groups may be attributed to supernatural intervention, especially if the deaths are viewed as premature, unexpected or sudden (Reid & Mununggurr, 1977).

There are many beliefs intertwined with supernatural intervention and sorcery. There is the belief that: sorcery exists in many forms, its effect is to manipulate and alter behavior and cause morbidity and mortality; sorcerers can be specialists or non-specialists; distant groups have the most potent sorcery and are the most feared; many diseases come from dangerous, secret sites - they are manifestations of the forces or power emanating from those sites; unskilled or uninitiated people may release forces from a dangerous site, by disturbing the site; sorcery is carried out in secrecy; retribution sorcery is directed serially at members of a family or lineage therefore the serious illness or death of one member is followed by the illness and death of others; and a traditional healer can apply counter measures to identify the cause and source of illness and death but the healer should not interfere if it is the result of legitimate punishment (Biernoff, 1982).

The concept of supernatural intervention and sorcery plays an important function as "it explains why one person died or became ill at a certain time and not another" (Reid *et al.*, 1977, pg. 39). It provides the explanation of 'why me' and 'why now', which cannot to be answered in

terms of Western medical theory. It provides the ultimate cause of the event. It is also important to note that the destructive effects of sorcery are not only limited to the 'offender', but can also be felt by their families and descendants (Reid & Mununggurr, 1984). Nevertheless, while the thought of sorcery raises consciousness, the Aboriginal people do not live in constant fear of it. (Reid & Williams, 1984). Sorcery provides an explanation, which is applied retrospectively, to justify the cause deaths, serious illness or injury (Reid & Williams, 1984). At the same time, belief in sorcery has several negative effects: it is an illegal action, thus it leads to an implicit acceptance of lawlessness by the community; people's confusion about the cause of death or injury (assuming sorcery to be involved) leads them not to take responsibility for sickness, disease, or substance abuse, which is a frustration expressed by health professionals (Weeramanthri, 1997); families of law-breakers are concerned they will bear the brunt of punishment; much energy and time maybe spent on speculation about whether sorcery is to blame when someone becomes sick or injured in an accident (Aboriginal Resource and Development Services, 1993).

Supernatural interventions play a very important role in the traditional health beliefs of Aboriginal people as it may provide the 'ultimate' reason for why a person becomes ill. All health professionals interacting with Aboriginal people should have an appreciation of the effects this may have on the provision of health care.

The Role of Men and Women

In traditional Aboriginal culture, there are clear-cut divisions with respect to the roles of men and women in society. A woman's responsibility comprises all aspects of reproduction. This includes: menstruation, pregnancy, childbirth, contraception, and abortion (Arthur, 1996; O'Connor, 1993; Reid, 1979). Taboos pertaining to food are customary; especially during

mourning, pregnancy, and menstruation (Toussaint, 1989; Brady, 1995). On the other hand, a man's responsibility entails hunting, resolving conflicts, and dealing with issues relevant to the male anatomy (Arthur, 1996; Spencer & Schlemmer, 1997).

Any breaches with regard to these traditional divisions for gender, especially in health care (e.g. female nurse washing elderly initiated male Aboriginal, a female nurse teaching an Aboriginal man self-catheterization or a male doctor conducting a gynecological exam on a female) are likely to cause immense distress and shame (Spencer & Schlemmer, 1997; Sykes, 1988).

The concept of shame applies to those situations in which a person has been singled out for any purpose, scolding or praise or simply attention, in which the person loses security and anonymity provided by the group (Harkins, 1990). This occurs in situations in which one does not know the rules for doing the right thing and where whatever one does would be wrong because one should not be in the situation (Harkins, 1990) or by a person who acts, or who is forced to act in a manner that is not approved by the group and that is in conflict with social and spiritual obligations (Morgan *et al.*, 1997). Every health professional treating Aboriginal people should have an appreciation for this concept because of its influence on provision of services.

Preventative Care

The Aboriginal perspective on illness prevention demonstrates the extent to which social control is integrated with traditional health beliefs. For Aboriginal people, "good health is associated with strict adherence to approved patterns of behavior and avoidance of dangerous people, places and object'" (Biernoff, 1982, p. 148). Preventative measures to ensure good health and well-being are based on laws governing behavior and may include avoiding certain foods which are

prohibited during ceremonies or life crises (e.g. pregnancy or menstruation); obeying ritual prescriptions and taboos; taking care not to abuse one's land or trespass on the territories of others; avoiding prohibited sacred sites or approaching them with ritual protection; observing debts and obligations to others; containing anger, violence or jealousy; exercising caution in interactions with strangers; taking steps to avoid sorcery or open conflict with others; learning the hazards within the environment; avoiding all actions that might endanger the health of the family; observing the formalities and obligations of kinship; respecting and honoring the dead and safeguarding oneself against attack by leading an exemplary moral life, employing counter spells and charms (Reid, 1983; Peile, 1997; Taylor, 1977a; Gray, 1979). These methods of preventing illness link directly with what are regarded as the ultimate causes of illness under the Aboriginal model of causation.

Treatment

The first type of Aboriginal medical treatment is bush medicine. There are a myriad of substances used for bush medicine; most of which are symptom-specific (Nathan & Japanangka, 1983; Peile, 1997; Scarlett *et al.*, 1982; Saggers & Gray, 1991). Examples of bush medicine include herbal preparations, diet, rest, massage, restricted diet and external remedies such as ochre, smoke, and steam. Information about the use of bush medicine is common knowledge and is usually possessed by every adult (Nathan et al, 1983; Shannon, 1994, Gray, 1979; Berndt, 1964).

The second sources of treatment are traditional healers or the medicine men. These individuals are held with high regard in the community (Gray, 1979; Soong, 1983). The profession tends to be male dominated although there are female healers in some communities (Peile, 1997; Tynan, 1979; Saggers & Gray, 1991). Traditional healers have a variety of roles.

These roles include: providing strong spiritual support (Reid, 1983; Soong, 1983); determining the ultimate cause of a serious illness or injury (Nathan & Japanangka, 1983; Reid, 1983, Peile, 1997; Tynan, 1979); determining cause of mysterious deaths at an inquest (Nathan & Japanangka, 1983; Reid, 1983, Peile, 1997; Tynan, 1979); and employing counter sorcery to remove the evil influences causing illness (Reid, 1983, Tynan, 1979).

Traditional healers have a number of characteristics, which assist them in their healing roles: they share a common language and world view with their patients (Elkin, 1994; Peile, 1997; Saggers & Gray, 1991); there is an expectation of relief from the patient (Elkin, 1994, Saggers & Gray, 1991); the patient receives treatment in a familiar, supportive, non-threatening environment (Gray, 1979); and there is usually already a close relationship between the healer and patient with resultant faith in the healer (Gray, 1979).

There are also individuals within the community who can aid in healing process but are not considered traditional healers (Nathan & Japanangka, 1983; Reid, 1983, Peile, 1997; Tynan, 1979). Older men knowledgeable in ritual life may care for the sick (usually close kin) by singing for the patient. These healing songs are 'owned' by the singer who inherits 'ownership' from other older initiated men. It is inappropriate and ineffective to sing a healing song that belongs to someone else (Tynan, 1979). Older women may inherit a healing song; however these songs do not remove the influence of sorcery; rather they act to strengthen the patient to battle the effect of sorcery (Tynan, 1979).

While there are various preventative strategies in Aboriginal medical systems, treatment generally involves the use of bush medicine for specific symptoms and injuries, and traditional healers assist with any matter thought to have occurred due to supernatural intervention.

Thus, it is evident that the traditional medicine framework, emphasizes a holistic approach to health care and this is supported by treatments and medicine that are designed to meet the needs of the four elements of the person. The need for an approach that incorporates traditional medicine ideologies is also shown through the higher success rates of treatment programs that are based on these traditional principles. The implication that inequalities to health for Aboriginal people are, to some extent, related to the way that Western medicine is delivered is supported by the fact that, for example, "in client treatment focus groups [for substance abuse]…cultural elements were deemed to be the most useful to participants" (Jock et al, 1998, pg. 50)

Differences between Traditional Aboriginal Medicine & Western Medicine

When the Europeans began to settle in North America, the social and political composition of society began to alter. Settlers began obtaining control over the land base as well as all of its resources. It was necessary for the Aboriginal peopled to adjust from a lifestyle that was governed by the laws of nature, to a lifestyle dictated by the economy (Kuhnlein, 1993; Scott, 1994; Van Kirk, 1993). The physical displacement endured by the Aboriginal communities from their natural habitat where all aspects of life were interconnected with the environment, to reserves and settlements with a limited means of prosperity, led to extremely high levels of poverty. In response, the Aboriginal people became more reliant on the federal health care system in order to meet the primary health care needs; yet it appears that these needs were not met (Moffat & Herring, 1999; Scott, 1994).

Health statistics from the past and present indicate higher death rates for Aboriginal people in all areas of health (Moffat & Herring, 1999; Scott, 1994). The question of why this is the case, may be answered through an analysis of the fundamental differences that exist between

the paradigms of traditional and Western medicine. For the purpose of this discussion, Western medicine is defined as all the dimensions of health care that fall under the jurisdiction of the federal government of Canada and which are executed through the policies and agencies supported by Health and Welfare Canada (World Health Organization, 1997). .

Philosophical Foundations

The philosophical foundation for traditional and Western medicine reveals significant differences in their approaches to health care and health care delivery. The Medicine Wheel, which includes all facets of the environment and the spiritual world that maintain human existence, dictates Aboriginal traditional medicine. Thus, the self must consider, and be at ease with all the forces of nature in order to achieve balance and harmony, which in turn, results in good health (Montour, 2000).

Western medicine on the other hand, employs a very analytical approach to health. The body and the mind are regarded as separate entities that need to be medically treated as such. This is emphasized by the fact that Western medicine tends to classify symptoms and treatment of illnesses into different areas, such as internal medicine or psychiatry. In addition to creating a system where many specialists are needed to treat one individual, Western medicine does not acknowledge religious or spiritual interventions as contributors to illness or healing. In contrast to Aboriginal traditional medicine, addressing the spiritual needs of a person does not fall within the domain of Western medical practices (Shestowoski, 1993).

Structural Components of Health Care Delivery

A comparison of traditional medicine and Western medicine also reveals a difference in the structural components of health care delivery. These differences are associated with the

environments in which health care is delivered, and with the issue of power. To begin, traditional medicine is administered in a rather informal, unstructured environment (MacMillan *et al.*, 1996; Shestowoski, 1993). For example, many healing rituals performed by medicine men are performed in the outdoors. Again, this done in order to reconnect with the spirits of nature who are potentially responsible for the illness or to ignite the powers of healing that the medicine men may have (Morse *et al.*, 1991).

Alternatively, Western medicine is administered in a more formal, structured environment. In an impersonal manner, health care services are delivered in an atmosphere that is confining whereby the client must be compliant, thereby promoting passivity on the part of the patient. For example this can be seen when a doctor, after compiling a history of signs and symptoms, prescribes the necessary treatment only if he or she feels there is a problem with the patient. In contrast, traditional medicine allows the patient to determine if something is wrong and allows the patient to have input on the treatment (Morse *et al.*, 1991).

Power

Power, and the possession of power, as expressed in the patient-healer relation versus patient-doctor relationship, is also one of the most apparent differences between traditional medicine and Western medicine. Although traditional healers are seen as having powers to aid the sick in recovery, the healing is accredited to Creator of the spirit that is called upon by the healer. Furthermore, the traditional healer presents himself as equal with the patient by stressing the importance of the patient's participation in healing treatments and ceremonies (Morse *et al.*, 1991).

In Western medicine, the doctor is exclusively the healer. The inherent power of this position is visible by the vast array of credentials in the form of certificates on the wall of a doctor's office. Furthermore, difference in power is emphasized when the doctor is addressed as 'doctor', while the patient is addressed by a first name (Morse *et al.*, 1991; Shah & Dubeski, 1995). The consequence of portraying health professionals as authority figures is that it reduces self-advocacy and self-reliance because the control of health appears to be in the hands of someone other than the patient (Shestowoski, 1993). The power differential that occurs within Western medicine is further demonstrated in the guiding principles of the two paradigms.

Guiding Principles

Aboriginal traditional medicine and Western medicine differ with respect to two guiding principles. These principles pertain to the strategies used to diagnose illness and the interactions that occur between the healer/patient and doctor/patient for the duration of the treatment. (Morse *et al.*, 1991, Shestowoski, 1993) Traditional medicine uses a holistic approach to health care integrating multiple strategies to treat the patient. The simultaneous application of strategies is done to address all four components of the Medicine Wheel. Furthermore, it is believed that the use of multiple strategies can provide synergistic effects throughout the body resulting in a more successful outcome for the patient (Morse et al, 1991).

In contrast, the analytical nature of Western medicine, which fragments components of health into specialties, requires the need for several specialists to implement multiple strategies. This approach diagnoses an illness on the separation of physical conditions without acknowledging other internal or external factors that may contribute to the illness. A synergistic effect, in this sense, usually refers to the multiple side effects that the patient experiences as a

result of combining medications and treatments. Furthermore, the several specialists rarely come into contact with the patient at the same time; as well, they are less likely to be person who administers the actual treatment (Morse *et al.*, 1991).

Direct contact with the patient is also noted as a stark difference in the principles that guide each of these systems. The traditional healer remains in close contact with the patient through the duration of the treatment (Morse *et al.*, 1991). Interaction with the patient consists of continuous verbal support and the actual administration of the treatment by the healer. Verbal support not only provides comfort, but it invokes participation from the patient to speed the recovery process and at the same time, strengthens the relationship between the patient and the healer (Morse *et al.*, 1991)

In contrast, due to nature of the health care system, Western medicine produces doctors that spend minimal time with patients thereby failing to establish a meaningful relationship before, after, and during the process of treatment. In addition, a third party, usually a nurse, will administer the treatment thus perpetuating the passivity of the patient and the lack of continuity in care. Furthermore, the patient now has to develop an additional relationship whilst the energy might have been better spent directed toward the goal of healing (Reynolds Turton, 1997; Morse *et al.*, 1991).

The fundamental differences between traditional and Western medicine discussed above, represent only some of the dissimilarities between the two systems. It is also important to acknowledge that Western medicine, despite its apparent unsuitability for Aboriginal communities, has made innumerable contributions towards the advancement of treating and curing diseases, as well as designing information communication technology applications such as Telemedicine, to increase availability of health care to remote and rural communities.

Furthermore, it is not to say that the Aboriginal paradigm of health is superior to the Western medical approach. The Aboriginal medical model has limitations. One such limitation includes the restriction that traditional medicine places on its distribution of knowledge. From the Aboriginal perspective, medicine should not only include tangible ingredients, such as bush medicines, but should also incorporate the intangible aspect or spiritual dimension. As such, only those individuals deemed to have appropriate knowledge or connections with spirits and powers can effectively administer treatment. This severely limits the number of individuals that can help to improve health within a community in this manner (Janes, 1999; Malloch, 1989; Royal Commission on Aboriginal Peoples, 1996; Shestowoski, 1993).

To this end, there is much discussion in the literature on Aboriginal people that alludes to the possibility of integrating traditional medicine and Western medicine. The conflicts that arise from this proposition are examined in the next section of this paper.

Conflicts of Integration with Aboriginal Traditional Medicine & Western Medicine

The Nature of Medical Systems

Historically, the Aboriginal population of Canada had been placed in the position of subjection to the Canadian government (Van Kirk, 1993). With the imposition of what is coined by Moffat & Herring, (1999) as a "racial paradigm" (patterns of racial inequalities and oppression), traditional medicine remains at the scrutiny of policies and regulations dictated by Health and Welfare Canada (p.1828).

Any system of medicine, before it can be practiced, must endure a method of legitimization by Health and Welfare Canada. In today's economic and political climate, this method of legitimization requires accountability outlined in measurable terms. Unfortunately,

Western society's demand for scientific basis for medical care and the systematic recording of knowledge contradicts the philosophies of traditional medicine. Not acknowledging the validity of traditional medicine as the product of generations of orally transmitting the medical knowledge, the lack of scientific proof deemed and still deems, the Western medical system dominant over the Aboriginal traditional approach. (Janes, 1999; Shestowoski, 1993).

Conceptualizations of Illness Prevention & Health Promotion

A second source of conflict of integration may arise from the discernable difference in Western and Aboriginal conceptualizations of illness prevention and health promotion. Based on medical models, Western medicine designs and implements large-scale interventions to prevent illness and promote healthy behaviors. In contrast, although Shestowoski (1993) suggests that traditional medicine emphasizes the prevention of illness, she concedes that it is not known how traditional healers engage in this activity (p. 20). Two examples of Aboriginal health practices support this statement.

In traditional medicine the Aboriginal patient determines when something is wrong and then goes to healer for the purpose of finding a cure. Western medicine differs in this respect because it encourages "'patients to come for regular checkups to ensure normality'" (Morse *et al.*, 1991, p.1362).

The lack of emphasis on illness prevention is further suggested by the Aboriginal attitudes towards immunization. Seeking a treatment that induces illness, such as the side effects of immunization itself, in order to prevent illness, is incomprehensible to the traditional way of thinking. The problem is that Aboriginal people do not find illness prevention to be a meaningful concept. Support for this is found in the research done by Hislop *et al.*, (1996) and Band *et al.*, (1995) on Aboriginal women and their lower participation rates for cervical cytology

screening compared to women from other cultural backgrounds. They suggest that the "health promotion philosophy" of Aboriginal women is contradictory to the illness prevention stance that cervical screening education tends to form. (Hislop *et al.*, 1996, p. 1705).

In summary, there are many conflicts that arise from the integration of traditional and Western medicine, mainly due to power differences and conceptualization of illness. Furthermore, it is evident that the Aboriginal people have not been receptive to health prevention and health promotion approaches of improving of health. This is not to suggest that health prevention and promotion interventions should be avoided; however it does present strong implications for determining the most appropriate methods of health care programming and it emphasizes the need for cultural competence, in working with Aboriginal populations.

Understanding the Contextual Issues: Aboriginal Health and Well-being

Determinants of Health

It is critical to understand what health means in an Aboriginal context, as described by the Medicine Wheel. Too often a narrow definition of health permeates the literature whereby programs and resources respond almost exclusively to an individual's loss of health (acquiring disease) and neglect the underlying determinants of ill health (O'Neil, 1999).

The importance of health determinants has been validated in numerous studies. These studies have shown the connection between health status and a number of factors including social and economic forces, psychological influences, physical and genetic factors, and cultural elements. As well, international comparisons of per capita spending, life expectancy, and morbidity rates have shown that countries, which have high health expenditures, do not necessarily have the best health indicators. Beyond a certain level, investments in health care

services do not equate to the same magnitude in improved health status. This suggests that there are other factors that must be considered for improving population health. Certainly the situation in Aboriginal communities provides real life examples of the impact of health determinants such as poverty, nutrition, living conditions and unemployment on individual and community health and well-being. Despite the strong arguments presented, the Canadian health system has retained a primary clinical focus with respect to Aboriginal people. The health system available to most Aboriginal people is mainly reactive, health care services, which have not yet fully embraced, in a practical sense, the concept and importance of health determinants (O'Neil, 1999).

Politics

Mainstream health care, as it has evolved in relation to Aboriginal communities, has been shaped by a century of internal colonial politics that have effectively marginalized Aboriginal people from the dominant system of care (Browne *et al.*, 2000; Smylie 2000). Despite the current and still problematic thrust towards health transfer, there are many issues that may confound the best efforts to negotiate the control and delivery of health care services to Aboriginal communities. It is critical to understand that conventional clinical approaches may not enmesh with traditional Indigenous values or with the realities of contemporary settlement. There is a "need to rethink the applicability of different models of intervention from the perspective of local community values and aspirations" (Kirmayer, 2000, p.613). Indeed, if we are to understand "healing as the rebuilding of nations" and as a process of decolonization, then we will also come to understand the ways in which health is effectively articulated at the level of the individual, family, community and nation (Warry, 1998).

Despite the problems, health care services and provision have ameliorated considerably since the First Nations and Inuit had initial contact with Western medicine. The earliest form of medical health care arrived in many communities with the missionaries and priests, many of whom were more inclined to preach rather than save lives. Nevertheless, the missionaries did provide service prior to any other medical attention to Aboriginal peoples in Canada (Kerln 1996). A lot has changed since the initial contact and there have, without a doubt, been improvements in health care delivery to Aboriginal peoples in Canada. These services, though, remain inadequate and underestimate the link between control of health services and health disparities (Kerln, 1996).

Health care services are provided to Aboriginal peoples living on-reserve or in remote communities through the federal government. Those services, a treaty-based federal responsibility, have been a struggle to maintain, regardless of their adequacy or sufficiency. While First Nations have requested an autonomous locally accountable system of health provision as an Aboriginal and Treaty right, the government will not acknowledge this request. Nonetheless, the federal government does recognize a special relationship between the federal government and First Nations and since 1989, has been instituting a Health Transfer Policy (Kerln, 1996).

Introduced in 1974 as the Indian Health Policy, the current Health Transfer Policy emerged out of a federal government initiative to integrate health care into the larger national health care system. From the period of the late 1960's, when there was a federal push towards devolution of special services, first to provinces and then to Aboriginal peoples, and then the 1989 government approval of Health Transfer Policy, representatives of the First Nations have

fought to retain as much autonomy in health care delivery as possible despite the constraints inherent in the negotiation process (Kerln, 1996).

The First Nations and Inuit Health Branch (FNIHB) of Health Canada, with regional offices in every province, support the delivery of public health and health promotion services to on-reserve and Inuit communities. It also provides drug, dental and additional health services to First Nations and Inuit people regardless of residence. Included within the FNIHB are the Community Program Directorate, Primary Health Care and Public Health Directorate, Non-Insured Health Benefits Directorate, the Office of Nursing Services, the Office of Community Medicine, the Business Planning and Management Directorate, the Strategic Policy, Planning and Analysis Directorate, and the Chief Executive Advisor of First Nations and Inuit Relations. In addition, the Northern Secretariat was created in the fall of 1998 to provide equitable program delivery to the First Nations and Inuit living in the Yukon, the Northwest Territories and Nunavut (NAHO, 2002).

The Health Transfer Policy has led to an improvement of health in Aboriginal communities, generated and maintained by the communities themselves, and does acknowledge a special relationship between First Nations and the federal government. Nevertheless, the government has not recognized health as an Aboriginal treaty right and has summarily removed it from the realm of treaty negotiations (FNIHB, 2002). Essentially, this is the fatal flaw of the Health Transfer Policy. It transfers services but retains the pre-existing dependent relationship. For example, the federal government must approve First Nations proposals for community health plans, there is a non-enrichment clause that freezes funding from the time of transfer, the transfer policy does not formally recognize the role of traditional healers in the transfer agreement, and it does not fund the training of First Nations health care professional (Speck, 1989). Ultimately,

the argument presented by the First Nations is that health care services alone are unlikely to result in significant improvements in the health status within First Nations. There is a need for community control over economic resources, political autonomy, improved standards of living, as well as changes in the attitudes of non-Native Canadians, to significantly reduce health disparities (Speck, 1989).

First Nations, Inuit and Métis, living in urban centers also find themselves excluded from many of the service and benefits provided by FNIHB. Aboriginal people moving into or living in urban centers, encounter various health care provision challenges as they ostensibly exit their community's health network and enter into the provincially funded public health care system. While those on-reserve communities have been extensively studied, the health status of those living off-reserve remains to a large extent ignored (McCue & Wigmore, 1990).

As Goldenberg (2001) further explains:

> Just as most demographics are difficult to obtain for urban Natives, their health information is often inaccurate, inaccessible or otherwise buried within the health information of the larger non-Aboriginal population or of the on-reserve Aboriginal population….The lack of accurate information is compounded by a lack of political will, since the federal government mostly concerns itself with the [statistically and organizationally relevant] health needs and patterns of Indian people on reserve…(2001, p.31).

Thus while there are various successful culturally appropriate urban initiatives across urban Canada, such as Anishnabe Health in Toronto, Ontario, there remains the problem of inadequate assessments of health care needs, barriers to timely and appropriate care, and scarce resources to offer appropriate services to the urban, and particularly poor, Aboriginal women, men and children (Benoit *et al.*, 2003).

Research, Programs and Services

The theme that is reiterated throughout various studies and reports is that those who are the poorest and most disempowered, are the least likely to be able to change or remove themselves from their immediate circumstances. Referred to as an "endless circle of disadvantage", many Aboriginal people in Canada are caught in a seemingly endless circle of poverty, family violence, educational difficulties, ill health and violence (Waldram *et al.*, 1995). Underlying that cycle is the distressing legacy of colonialism; this includes the direct and indirect present-day effects of a history loss of lands and political, cultural, economic and social disenfranchisement. Waldram *et al.*, (1995) further explain:

> In examining Aboriginal health and health care, it is important to move beyond simplistic explanations, an approach which stresses the political economy of health seems more appropriate given the status of the Aboriginal people as indigenous, colonized minorities in their homeland. This approach should address the issue of culture, biology, but also carefully investigate historical events and policies, as well as socio-economic factors and the nature of the Canadian state and Canadian society. In doing so, we not only see the victimization of Aboriginal peoples through colonization, loss of lands, and various forms of racism, but also see Aboriginal people as individuals reacting to an oppressive situation. Any approach which fails to consider Aboriginal people as active in response to their colonial situation, rather than simply as passive victims, will fail to comprehend not only the past changes in health status and health care, but more importantly the future direction that will be taken in these areas (1995, p.270).

The path towards a reduction in disparities in First Nations, Métis and Inuit health status is primarily linked to a larger political will to truly comprehend the relationship between inequality and ill-health. Steps towards recovery and recuperation have begun and are continuing to occur at the community, regional and national levels. For example, the National Aboriginal Health Organization, the National Native Alcohol and Drug Abuse Program, the First Nations Chief's Health Committee of British Columbia, the National Indian and Inuit

Community Health Representatives Organization, the Aboriginal Healing Foundations, the Kahnawake School Diabetes Prevention Project, the Native Mental Health Association, and the CIHR Institute of Aboriginal People's Health, all plan programs as steps towards providing a better future for the health of the Aboriginal peoples of Canada (Waldram *et al.*,1995).

Nonetheless, gaps remain in the implementation of health initiatives for the Aboriginal peoples of Canada. The most significant problem is the lack of control of a comprehensive health care program. While there are many initiatives being created by and for the Aboriginal nations of Canada, there is inadequate control of the resources and many health priorities remain unaddressed. In addition to this lack of control, there remains a scarcity of research that is inclusive, engaged and empowering. First Nations, Inuit and Métis people, particularly since federal health services established in these reserve communities, have been literally captive specimens for all sorts of researchers, investigators, government officials, consultants and academics. Certainly documentation has been and is needed to determine required levels of health and other services and whether programs are effective in accomplishing their goals. However, there is a general consensus among many Aboriginal people that this research has primarily been one-sided; that researchers invade communities for motives of personal career enhancement, academic publishing and financial gain. Perhaps there would be less cynicism had Aboriginal communities in the past participated in the research and received concrete, positive benefits.

It is evident through the analysis of research ethics in an Aboriginal environment, that past research activities have contributed to the colonizing process and furthered First Nations' oppression. Due to the harsh realities of the situation facing First Nations communities, the vast majority of publicly disseminated research has projected a negative image of Aboriginal people

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in the media, as unhealthy mentally and physically, unemployed, poorly educated, marginalized and vulnerable. The negative implications that this has had on the esteem and pride of a people, is difficult to conceptualize both in community and individual terms. The lack of hope, which is implicit in many descriptions of ongoing high rates of mortality and morbidity, may well be a contributing factor to the perpetuation of a stereotype rather than to offer valuable information for positive health behavior change (O'Neil, 1998).

Epidemiological research on Aboriginal health can function as a powerful social instrument for the construction of Aboriginal identity. International research has shown that public health surveillance systems perform disciplinary and regulatory functions in society independent of their overt purpose of tracking health conditions (Armstrong 1983). This analysis demonstrates the ways in which knowledge is constructed about sectors of society, which reinforces unequal power relationships; in other words an image of sick disorganized communities can be used to justify paternalism and dependency (O'Neil, 1998).

External analysis of epidemiological data often constructs an image of Aboriginal communities as desperate, disorganized and depressed (O'Neil, 1998). This image is usually created and manipulated with the intent to provide evidence for greater need for health care resources in the Aboriginal community. However, this image is often reflected through the Canadian media to the general public with quite different results. This image can reinforce racist and other stereotypic images held by Canadians generally of Aboriginal people. This image is also sometimes internalized by Aboriginal communities and individuals and reinforces dependency relationships (O'Neil, 1998).

What is now required are research initiatives that lead toward a clearer examination of, and emergence from, these disparities. That research must be conducted in accordance with the

needs and aspirations of First Nations, Inuit and Métis people. Studies need to examine differences within and between age groups, genders, levels of socio-economic status, education, and other significant markers of both identity and inequity. Studies of health must be interpreted broadly enough to include individuals and communities as well as studies of housing, water, education, development and resource extraction, in addition to the different social and cultural valuations of health and empowerment. It cannot be presumed that people of First Nation, Inuit and Mentis are unchanged, single or uniform; there is a diversity of cultures and clinical challenges.

We must also remain cognizant of the very real cultural and social barrier that may exist between First Nations, Inuit and Métis individuals and health service providers in communities and urban centers. This type of awareness and comprehension will contribute to the effective reduction of both the inequities and the disparities of health. Research and policy needs must reflect the contemporary realities of Aboriginal health and well-being, including the individual and community-based effects of health disparities (violence, suicide, HIV/AIDS and diabetes), as well as the direct (housing, education, employment, and adequate and appropriate health services) and indirect (colonization and racism) roots of those disparities (NAHO 2003, IAPH 2003).

Strategies for Health Research, Programs and Services

Capacity Building

There is, appropriately, a growing call for decolonizing methodologies in Aboriginal health research and program initiatives. One strategy is building the capacity of Aboriginal communities and local organizations, to promote health. It is important to keep in mind that

health promotion initiatives must acknowledge, affirm and reflect the values of Aboriginal culture. Culturally appropriate and effective health promotion programs have the potential to empower and build the capacity of communities to attain a greater sense of well-being. However, there is a need to have community input at all levels of planning, supported by the broader community and the health care system, so as to respond to the health concerns and issues in an effective and sustainable way (Ribeiro, 2002). This practice should also incorporate strategies to build community ownership, as well as include programs that are in accordance with the needs and motivations of the community (Horton, 2002). This type of an approach provides an opportunity for the development of skills in effectively promoting Aboriginal health, improved provision and distribution of resources, and a potential increase in the commitment from the health care system to Aboriginal health promotion. However, to begin this process, governments and organizations need to engage in meaningful dialogue with communities to establish priorities, encourage empowerment, self-advocacy and motivation, as well as conduct research that is successfully collaborative through community engagement (Ramirez & Quarry, 2004).

Empowerment

Empowerment is viewed as a process whereby communities take ownership of their lives and environment. This process aims to build on the existing strengths and abilities within the community. An empowered community is a competent community. In Webster's New World Dictionary (Neufeldt, 1988), competence is defined as having sufficient resources to take care of one's needs. This implies that the community must have the ability to deal effectively with unexpected problems or threats to well being. In contrast, powerlessness is an inability to affect one's destiny. Powerlessness is not just a subjective feeling of a lack of power or control over one's destiny; it also includes having an objective lack of social, political, and economic power

to effect change in a complex society. Powerlessness has been found to be a strong risk factor for illness and disease (El-Askri *et al.*, 1998; Wallerstein, 1992). Thus, empowerment would be a strong protective factor against disease and illness. To increase community competence, it is critical to facilitate the empowerment of the individual community members as well as the empowerment of the community as a social unit. Empowering individuals entails gaining skills and increasing self-esteem thereby increasing control over one's life. On the other hand, empowering the community focuses on increasing citizen participation, strengthening social networks, and encouraging a sense of community identity (Israel et al, 1994; Wallerstein, 1992). It is important to make a distinction between empowering individuals and empowering communities because it is possible to have a community with every individual feeling empowered and still not have an empowered community. Only by collaborating as a social unit will the community be able to accomplish the numerous changes needed to address major determinants of health such as socioeconomic conditions, physical environment, and access to quality health care (Washington State Department of Health, 1996).

Self-Advocacy

Self-advocacy is the ability to seek, evaluate and use information to promote ones health. Self-advocacy is often an outcome of an individual's socio-cultural orientation, which refers to the learned ways of doing, feeling and thinking. It also includes religious beliefs, rituals and language (Sinnema, 1991). Socio-cultural orientations are often transmitted from family members, friends, community members and mass media. These external influences can mould attitudes towards health, life skills, self-advocacy and self-concept. Individuals who come from 'present'-oriented cultures, such as the Inuit and First Nations People, rather than 'future'-oriented cultures, are more inclined to have difficulty making immediate choices that affect their

future health.   Many Aboriginal languages do not even contain past and future tenses. As a result, individuals who speak these languages are likely to focus on the present rather than long term consequences. This is significantly different from those individuals who speak English as their first language; a language that emphasizes time and numeric order (Vessey & Sloand-Miola, 1997).

The socio-economic status of an individual is also an important factor in determining self-advocacy. Socio-economic status is not only indicative of financial resources but it is usually a reflection of educational background as well. Higher socio-economic status provides individuals with this sense of confidence or entitlement, not often seen in poorer families; they expect to accomplish more and receive more through the duration of their lives. Individuals from lower socio-economic backgrounds may have less motivation for behavior change just because they have less sense of their future and their control over it (Vessey & Sloand-Miola, 1997).

Motivation is the force that moves a person towards a specific action (Sinnema, 1991). It can be intrinsic, coming from within, or extrinsic, coming from external forces such as parents or the community. Both internal and external motivating factors can play a role in changing health behavior (Vessey & Sloand-Miola, 1997).

Motivation is often influenced by interplay of personality traits, developmental level, knowledge, socio-cultural background and previous experiences. Individuals who perceive benefits from engaging in self-advocacy behaviors are more apt to take action and control of their well-being (Ribeiro, 2002).

Participation

Participation encompasses a wide variety of activities from consultation with the public to capacity building. The literature documents a myriad of reasons for organizations, especially in health care, to engage the communities they serve. To maximize effectiveness and efficiency, the system should demonstrate that is providing the right services, to the right people, in the right manner. Community engagement, from the first stages of program and service development to evaluation, can provide an important source of information and ensure a high level of accountability and achievement of appropriate outcomes (Ribeiro, 2002). Furthermore, the design, implementation, and evaluation of services require decisions to be made in consultation with the stakeholders at several stages along this process. Though service providers can provide expertise on many aspects of services, the communities or end-users, are more knowledgeable and capable of making decisions that impact access to, and satisfaction with these services (Horton, 2002). Community engagement also leads to more effective decisions and a more sustainable system, where service are not developed or continued if they are not meeting needs of the target population (Uphoff, 1988). In addition, engaged communities will often develop solutions to community issues that are more holistic, integrated, and creative than those with little or no public input. Often these ideas will also be cost effective as they involve, to some extent, some form of voluntary community participation (Horton, 2002). Community engagement is also beneficial, as a vehicle for empowering local people in the communities who are feeling a loss of control over their infrastructure and lifestyle. A renewed interest in and ownership of their local health services is an additional outcome of engagement. It also encourages a range of disparate and traditionally inwardly focused stakeholders to work together in a unified service planning process. In addition, by conducting community consultations, fears

of changes to, and possible losses or additions of local health services, are allayed. Conducting an inclusive consultation also communicates that changes are necessary for the health services to be sustainable, but that these changes will take into account the wishes and feelings of local residents.

Community Partnership

It is critical to understand that community partnership entails the sharing of power and responsibility rather than simply doing what the researchers and professionals have recommended. "Only when issues are selected by the community itself can a real sense of `ownership' emerge, and this sense of ownership of the organization is critical to empowerment and to the ultimate development of competent communities" (Minkler, 1990, p. 271). Community competence refers to the ability of the community to engage in effective problem solving. There should be a collective analysis of the community's strengths and needs to create an appropriate agenda, rather than outside researchers and professionals assessing the problem and determining solutions. This is of paramount importance if the community is to reach its current objectives and future goals.

Cultural Responsiveness

Cultural responsiveness plays a key role in establishing good working relationships based on trust. It is important for researchers and professionals to take the time to understand the cultural factors (beliefs, values, and customs) that affect interpersonal relationships. The researcher or professional must take initiative to study the cultural make up of the community and learn about the history of the different ethnic groups in the community (Gonzalez *et al.*, 1991). In addition, when designing or delivering public health services, health professionals must be conscious of

the cultural factors that influence the meanings of health and illness from the perspective of the community members. Any cultural influences affect health-seeking behaviors will have a direct effect on community health status and on the acceptance by community members of any health promotion or illness prevention initiatives (Chrisman, 1977). Although specific health seeking-behaviors are unique to individuals, it is evident that there are patterns that can be identified within the illness belief systems of a given culture (Kleinman *et al.*, 1978). It is essential to have community representatives from various cultures among the group of individuals working on program planning. Through the community ownership acquired through the development and implementation of health of initiatives for any given health issues, the hope is that the interventions will then be culturally relevant and appropriate. Cultural factors will also have an effect on the acceptance of the principles of self-help, felt needs, and participation; especially in those cultures where these principles are not necessarily valued or viewed as desirable (Stone, 1989).

Key Competencies for Consultants, Researchers and Professionals

Caring

Human caring is one of the most basic and universal components of health care. The nature of caring has been examined in health studies using various methods. However, caring as a concept remains vague, and there is no universal definition. Nonetheless, Watson & Lea (1998) suggests that caring involves common elements such as the will to care, the intent to care, and caring actions. Swanson (1991) proposed the following five themes that demonstrate caring: knowing, being with, doing for, enabling, and maintaining belief. More contemporary themes of caring in health include such terms as interest and concern, liking, giving, compassion, and commitment.

The definition of caring that will be used in this study includes attitudes, judgments, and actions that show support to the individual and community, as well as the professional skill.

Cultural Self-Awareness

Campinha-Bacote (1999) suggests that cultural self-awareness is the intentional, cognitive process in which health care providers acknowledge, appreciate and become receptive to the values, beliefs, practices and problem-solving strategies of the target community. Observing others' behaviors through one's own personal values and beliefs system is similar to looking through a filter or screen. Removing it may not be possible, but acknowledging it allows for more insightful interpretation of behavior. By being conscious of one's own cultural biases, unintentional influences can be removed. However, this awareness requires the assessment of one's own prejudices and biases towards diverse groups, as well as an in-depth exploration of one's own cultural background (Campinha-Bacote 1999). This step is critical because people have a tendency to be ethnocentric; that is, viewing others unconsciously by using their own group as the standard for judging others.

Cultural Sensitivity

Cultural sensitivity is the desire and effort to design and deliver programs and services in a manner that is appropriate and responsive to the needs of the population (Doyle Liu & Ancona, 1996; Rorie *et al.*, 1996). Although the importance of displaying cultural sensitivity in marginalized and minority communities has been well documented, the term cultural sensitivity has been defined in various ways. Caudel (1993) defines cultural sensitivity in the context of community-based care; that is, awareness, knowledge, and implementation of specific issues that are important for the planning of direct and indirect services for the community.

Quite often, cultural sensitivity is used interchangeably with cultural awareness. However according to Clinton (1996), awareness is actually a precursor of cultural sensitivity and refers to a state of being conscious of oneself as a cultural entity. Similarly, Teufel (1997) perceives cultural awareness to be the cognitive recognition of culturally unique behaviors. Furthermore, he views cultural sensitivity as a concept that includes both cognitive and affective functions. For this study, cultural sensitivity refers to attitudes, perceptions, and values that show heightened awareness of the provider's own culture and that of the population being served. In community-based care, the sensitivity would then be focused on the relationship with individuals and families whereas, in community health care, the sensitivity would be focused on culturally sensitive aspects of health program development.

Cultural Knowledge

Cultural knowledge refers to knowledge of integrated systems of learned behaviors that are characteristic of members of groups as well as their system of attitudes, feelings, and values (Sawyer et al, 1995). Hence, the goal of cultural knowledge is to comprehend the patient's worldview. This involves acquiring knowledge regarding specific physical, biological and physiological variations amongst ethnic groups (Purnell, 2000).

While cultural knowledge is useful for consultants, researchers and professionals, it cannot be seen in isolation. A realization that culture is not static, but dynamic, must also be appreciated. Cultural knowledge can create an understanding of the patient's worldview rather than an acknowledgement of the validity of the patient's current perceptions. However, in order for the latter to be achieved, health professionals need to apply 'cultural safety'. This has been defined (NZNO 1995, p. 6) as:

. . . A manner which affirms, respects and fosters the cultural expression of the recipient. This usually requires health professionals to have undertaken a process of reflection in their own cultural identity and to have learned to practice in a way, which affirms the culture of clients and nurses. Unsafe cultural practice is any action which demeans, diminishes or disempowers the cultural identity and well-being of an individual.

For this study, cultural knowledge refers to the cognitive understanding of community culture including specific beliefs and behaviors. When discussing knowledge or understanding of culturally different health values, beliefs, and practices, stereotyping is possible; nevertheless, generalizations that acknowledge differences are necessary (Galanti 1997). Program protocols can build in importance on knowledge so that health providers develop referral systems using all appropriate resources.

Cultural Skills

For consultants, researchers and professionals, cultural skills connote abilities, roles and functions in a community setting. Possessing cultural skills means having the ability to conduct a culturally based assessment (systematically examine beliefs, values, and practice of individuals, groups, and communities) to determine health care needs within a cultural context (Buckwald, 1994). Cultural assessment provides the health professional with data on which to base trans-cultural community-based care for families, as well as program planning to promote community health. This also prevents the health care provider from assuming that no cultural barriers exist based on the fact that the patients look and behave in the same manner as the health professional (Buckwald, 1994).

The importance of speaking the local language has been well described (Jezenwski 1995, Campbell & Campbell 1996). Nonetheless, if the care provider does not speak the language of the patient, communication by gestures, as well as other non-verbal behaviors is important and

interpreters may become an essential part of the community-based health care team. The act of cultural bridging as a facilitator or advocate has been emphasized in community health settings (Jezenwski 1995, Campbell & Campbell 1996).

In conducting research or providing services, communication in the form of advocacy is a necessary cultural skill (Jezenwski 1995, Campbell & Campbell 1996). Advocacy entails not only recognizing racism and ethnocentrism, but also taking action about it on behalf of the community (Rorie *et al.*, 1996, Lindsey *et al.*, 2001). Advocating for program development may include lobbying government officials to create culturally meaningful health policies. Andrew (1999) emphasizes that critical thinking is a key component of cultural competence because it helps caregivers avoid stereotypes, which may result in misjudgment, or perpetuate prejudices and discrimination against members of certain cultural groups.

Cultural Encounter

Cultural encounters occur when consultants, researchers and professionals engage directly in cross-cultural interactions with patients from diverse backgrounds. Habitually, researchers and professionals assume that because they have studied a specific culture on paper or interacted with a few individuals, they are well informed about that group. Literature, as well as individuals, may not always express the accurate beliefs, values and practices of that specific cultural group because greater variation may exist within and across cultural groups. Interacting directly with individuals within the target cultural group is critical to refine or modify one's existing beliefs of that cultural group. Face-to-face experiential encounters can also validate, negate or contradict what other individuals have said in the literature or in person. Failure to interact with individuals from the cultural group may lead to stereotyping and inappropriate methods of health care delivery. Thus, this experiential knowledge will serve as a foundation for developing culturally

relevant interventions (Campinha-Bacote,1996). For this study, the aim of cultural encounters is the ability to send and receive both verbal and non-verbal messages accurately and appropriately within the context of the community. This endeavor may be challenging but often, good intentions and common non-verbal communication styles may be interpreted as offensive to specific cultural groups.

Valuing Differences

Consultants, researchers and professionals need to consider the issue of diversity among their staff and patients; for example, when non-Aboriginal health professionals are working with Aboriginal patients and health workers within a community. The concept of addressing diversity is premised on recognizing diversity and difference as positive attributes of individuals and organizations, rather than a problem to be resolved. This is a relatively new approach and can be seen as a response to feelings of dissatisfaction with conventional equal-opportunities strategies. This new emphasis, then, is focusing on building on positives, rather than seeking simply to eliminate or reduce negatives. As part of the move towards a managing diversity approach, Walker (1994) proposes a 'valuing difference' model. This model is based on four key principles: (i) People work best when they feel valued; (ii) They feel most valued when they believe that their individual and group differences have been taken into account; (iii) the ability to learn from people regarded as different is the key to becoming fully empowered; and (iv) when people feel valued and empowered, they are able to build relationships in which they work together synergistically and on an interdisciplinary basis. The principles of valuing of differences are relevant to consultants, researchers and professionals because they offer less reliance on a legalistic approach, which can easily become tokenistic. Rather, these principles acknowledge issues at the level of organizational culture, not just at a personal level. Nonetheless, addressing

diversity is limited in that it does not address power relations and the structural levels within societies; however, it clearly has more to offer than many traditional aspects of equality practice, which can be disjointed and tokenistic. In addition, given the deep-rooted attitudes, vested interest and structural inequalities that characterize modern organizations, a managing diversity approach will entail numerous obstacles and limitations because its success depends on changes in attitudes, structures and processes to render societies more equal (Walker, 1994).

The Health Care System

The health care system within a community depends on the successful integration of a vast array of other systems that serves as the base for community care. Conflicts within community health care can occur at the intersection of the cultural system, and the health system. Consultants, researchers and professionals are able to resolve issues between these systems by acknowledging and incorporating these systems into their health care programs thereby leading to client satisfaction and increased utilization of health care services. For example, by showing appreciation for an Aboriginal patient's traditional cultural and health systems, health professionals would be able to develop trust with a patient who exhibits fear of existing community health services (Zoucha, 1998). Furthermore, numerous studies demonstrate that positive health outcomes for the community are more likely to be sustainable if the community engages in the health initiative (Lindsey *et al.*, 2001). By advocating on behalf of the client, health professionals can invoke community participation. Therefore, intersections between cultural, community, and health systems will more likely have positive outcomes at the level of the individual, family or community.

Community System

According to Thompson & Kinne (1990) communities are comprised of individuals who share a common goal and are connected by locale, interdependent social groups, interpersonal relationship, and culture. Conventional definitions of community systems have focused on geographical aspects of a locally based group of individuals such as those found in a city or neighborhood (Geoppinger & Schuster, 1992). More recently, community and health professionals have expanded this definition to include specific aggregates (for example, HIV populations, elders, adolescents). (Baldwin *et al.*, 1998). In the proposed model, community is defined as both a cultural group and the target of health care services.

Cultural System

According to Thompson & Kinne (1990), the cultural system of a community gives rise to values, norms, beliefs, and a sense of connectedness for its members. Within this reality, or world view, an individual's purpose in life is defined, and appropriate, sanctioned behavior within the social group is prescribed.

Culture also affects the health status of group members (Hall, 1981). Furthermore, the health beliefs, and practices, drive the development and direction of health care systems (Kleinman, 1980). Thus it is necessary for community and public health care professionals to be conscious of, and trained in, culturally competent care.

Health System

Kleinman (1980) defines a health system as "illness beliefs, treatment choice, and outcomes of care of a group of people" (p.26). The definition of a health system for the proposed model incorporates culturally diverse s health beliefs, practices and health status, as well as cultural

factors, health beliefs, practices and health status that are influenced by demographic characteristics (age, gender, education, income, and marital status), lifestyle, and degree of acculturation.

Positive Health Outcomes

Positive health outcomes occur when communities are provided with culturally appropriate care. Smith (1998) identified seven positive results of culturally competent health care: (1) feelings of empowerment and respect for health professionals; (2) decreased anxiety/fear of the health care system; (3) greater percentage of cultural group members seeking and receiving appropriate health care; (4) greater client satisfaction with health care services; (5) improved education experiences for health professionals; (6) improved health status of minorities; and (7) health care professionals who value and respect one another. Overall indicators of positive health care outcomes as a result of culturally competent care will be reflected in community based care (improved health for individuals and families) and community health care (improved health of populations).

Conceptual Framework

From the comparison on Aboriginal traditional medicine and Western medicine, it is evident that no matter how open and unbiased the intentions of non-Aboriginal practitioners are towards Aboriginal people, they work against the backdrop of structural violence, racism, marginalization and a conceptualization of illness quite unlike their own. Only collaborative and culturally appropriate approaches that focus on the transfer of knowledge, skills, power and authority can hope to transcend these limitations. Therefore, there is, appropriately, a growing call for

decolonizing methodologies in Aboriginal health research and health care delivery, as well as in health promotion and illness prevention programs. One strategy is to build the capacity of Aboriginal communities and local organizations, to improve health. It is important to keep in mind that health promotion and illness prevention initiatives must acknowledge, affirm and reflect the values of Aboriginal culture. It must be recognized that Aboriginal identity itself can be a unique resource for health interventions. Knowledge of living on the land, community, connectedness, and historical consciousness all provide sources of resilience (McKnight, 1989). Culturally appropriate and effective health promotion programs have the potential to empower and build the capacity of communities to attain a greater sense of well-being. However, there is a need to have community input at all levels of planning, supported by the broader community and the health care system, so as to respond to the health concerns and issues in an effective and sustainable way. This practice should also incorporate strategies to build community ownership, as well as include programs that are in accordance with the needs and motivations of the community This type of an approach provides an opportunity for the development of skills in effectively promoting Aboriginal health, improved provision and distribution of resources, and a potential increase in the commitment from the health care system to Aboriginal health promotion and illness prevention. However, to begin this process, governments, academic institutions and research organizations need to engage in meaningful dialogue with communities to establish priorities, encourage empowerment, self-advocacy and motivation, as well as conduct research that is culturally responsive and builds partnerships through community engagement. Researchers and professionals, must also demonstrate caring and cultural sensitivity, they must become culturally aware through the acquisition of cultural knowledge and skills, and they must

engage in cultural encounters and value differences in systems of knowledge and understanding

in order for their work to result in positive outcomes for the community (Figure 2.3).

Summary

The Aboriginal peoples in Canada, First Nations, Inuit and Métis, come from extremely diverse cultures, yet they have all encountered similar socio-historical predicaments. In response, traditional philosophies and practices have been central to contemporary efforts by Aboriginal people to confront the legacy of historical injustices and suffering incurred from colonialism. Through individual and community based initiatives, as well as larger political and cultural processes, Aboriginal peoples in Canada are involved in reviving their own traditions, repairing the wounds and discontinuity in their transmission of traditional knowledge and values, and asserting their collective identity and power (Moffat & Herring, 1999; Shah & Dubeski, 1995). Reviving traditions refers to recovering and applying traditional methods of health and healing that were embedded in religious, spiritual and subsistence activities and that served to integrate the community and provide individuals with systems of meaning to make sense of suffering, illness, and death. These traditions were displaced and actively suppressed by successive generations of Euro-Canadian missionaries, governments and professionals and due to the socio-political structure of Canadian society, Aboriginal ideologies of health and illness have been forced to assume the position of second-class medical care (Janes, 1999). With respect to health, the loss of traditional medicine has resulted in devastating consequences for the Aboriginal people as evidenced by not only the alarmingly poor health of Aboriginal peoples compared to other Canadians, but also by the inappropriate attempts and subsequent failures of modern medicine to improve the health status of the Aboriginal people (Statistics Canada, 1998). Reviving these traditions therefore reconnects contemporary Aboriginal peoples to their historical traditions and mobilizes rituals and practices that may promote community solidarity. Any approach to health care delivery, health prevention and health promotion, must consider

these ongoing uses of tradition to assert cultural identity. By understanding the unique contributions of traditional medicine to Aboriginal culture, we will be able to recognize the ways in which Aboriginal people can gain significant improvements in their health.

It is critical to understand that biomedicine is also a tradition that conveys not only technical scientific knowledge but also whole systems of cultural values and practices. Recognizing the Western practice as a 'tradition' means understanding that the process of culture change is a two-way street. Thus, developing a collaborative research protocol will provide a framework from which researchers professionals, and communities can rethink the exchange of values on a more level playing field, as well as encounter and engage others' traditions and work toward and effective pluralism and hybridization of models and methods in the area of health or any other field of research (Royal Commission on Aboriginal Peoples, 1996; Saskatoon Health Unit, 1995).

Chapter Three: Methodology

This chapter is organized into six sections. The first section describes the context of the research with respect to the Fort Severn Community, Keewaytinook Okimakanak Research Institute (KORI) and the University of Guelph. The second section discusses the shift in methodology required to adhere to the KORI consultation guidelines. The third section defines the constituents of each stakeholder group (elders/leaders, community-based researchers and researchers). The fourth section provides methodological background for the study. This includes an overview of oral traditions in First Nations culture followed by a discussion of narratives as an appropriate method of inquiry. The fifth section outlines the data collection procedures. The sixth section discusses the trustworthiness of the data collected, the procedures used for data analysis and the emerging themes that resulted from the analysis.

The Context

The general aim of this study is explore stakeholder perspectives on the way research is conducted in First Nations community. The host organization for this research was Keewaytinook Okimakanak (KO) or Northern Chiefs, based in Balmertown Ontario, which represents six First Nations communities (Fort Severn, Poplar Hill, Deer Lake, North Spirit, Keewaywin and McDowell Lake) (Figure 3.1). In 2004, KO established a research division known as the KO Research Institute (KORI) to develop partnerships with academic institutions and develop strategies to improve the way research is conducted in the North. In 2005, KORI began developing Community Consultation Guidelines to brief researchers wishing to visit the KO communities (Appendix 1). The guide includes recommendations provided by KORI staff, community-based researchers and community members, which aim to ease the transition of a

researcher into a community, and to do so in a respectful and culturally appropriate manner. The

purpose of this study is to test the effectiveness of the consultation procedures recommended in

the guide as well as provide insight on other issues that may have been overlooked and need to

be considered as part of these procedures. Factoring population size, diversity and willingness to

participate, the community recommended by KORI for consultation was Fort Severn.

Figure 3.1: Map of Keewaytinook Okimakanak (KO) First Nations (Knet, 2002)
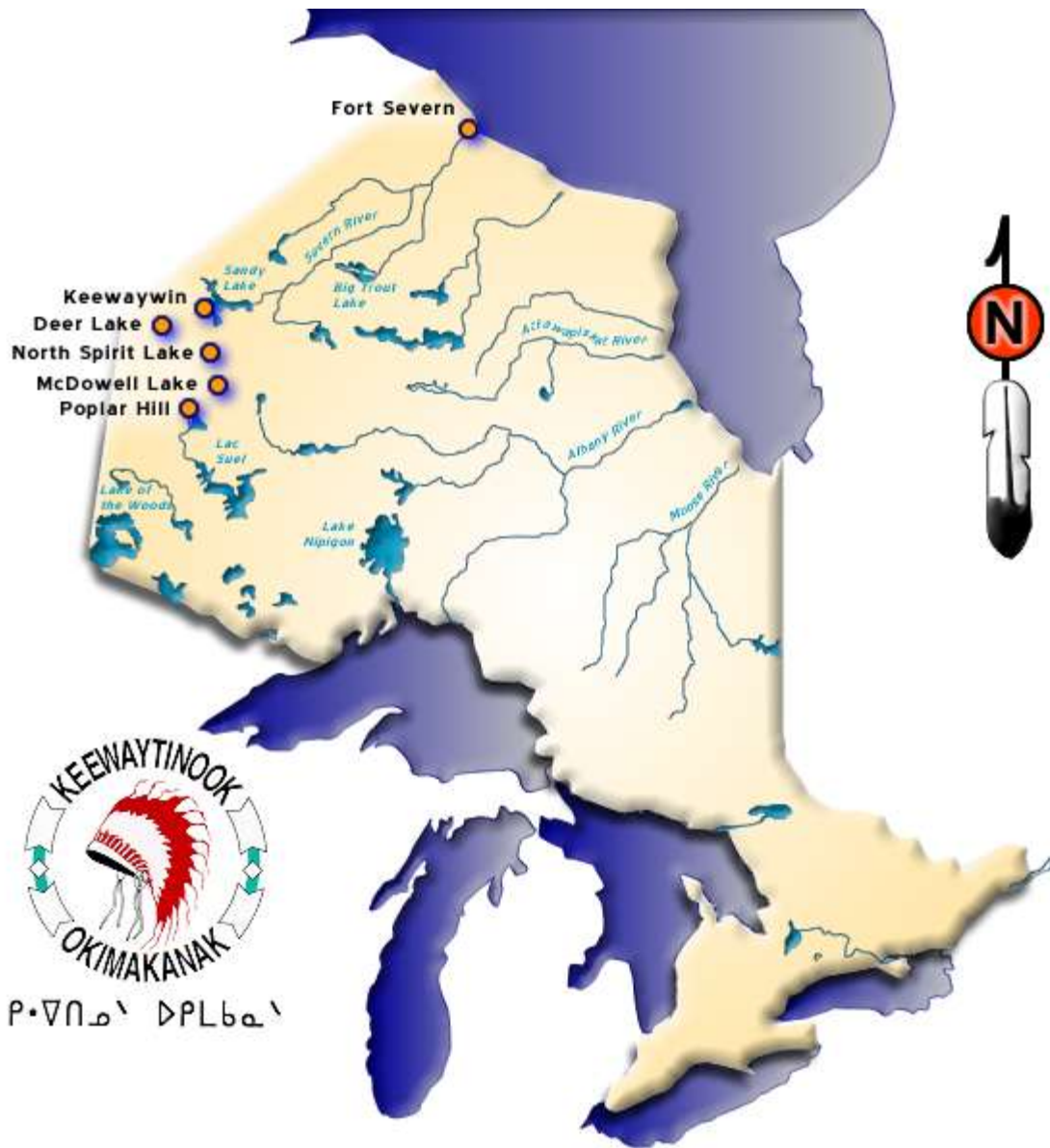
Implications of the KORI Consultation Guide: Preparation for Research in the North

Developing and testing the effectiveness of the KORI Community Consultation Guidelines and the importance of doing so occurs in the context of a history of colonization, oppression, and lack of enfranchisement. Academia has had a less than honorable part in this history, often, in the past, treating the First Nation as field laboratories (Piquemal, 2001). First Nation perceptions of research practices have emphasized their subject status, in which academics have been seen to enter communities, gain preemptory permission to conduct their work, collect their data and leave, with little or no feedback and perceived value to the community. Some research has been completely ignorant of ethics especially in cases where secret and sacred materials have been published and the practices of the people have been sensationalized. More recently, some research findings have had detrimental effects on the community concerned, when headlines in the media have reinforced stigmatizing attitudes and prejudices rather than incited the appropriate program response.

The KORI Consultation Guidelines are a response to past practices and provide a template for ethical and context appropriate research. In order to develop a long-term partnership with First Nation communities and proceed to work with them on a continuing basis, these guidelines necessitate understanding the nature of the community and establishing the appropriate mechanisms for consultation prior to conducting any fieldwork. As a non-First Nation researcher, following these guidelines for the first time was not unproblematic; in fact, it necessitated a significant shift in my methodology to account for the definition of 'community', the accommodation of very different communities within the First Nations, the complex gate keeping that operates at different levels, the various community structures and process, and individual perceptions of the goals and benefits of the research.

In most academic institutions, research only becomes possible when the applicant completes an ethics form that satisfies a Research Ethics Board (REB). The form focuses on a number of important issues. The applicant is expected to demonstrate in writing that the research discourse has been sufficiently mastered, as well as showing sensitivity to and awareness of potential harm, direct or indirect methods of recruitment, to cautious access procedures, to the particulars of formulating and claiming informed consent, to the propriety of questions to be asked, to obtain proper approval from organizations and communities, to the complete identification of the researchers to be involved, to the definition of the actual source of funding, to plans for future use, storage and ultimate destruction of the data, to the nature of perceived risks, to the types of future benefits expected, to ways of protecting confidentiality and anonymity, to maintaining the promised confidentiality over time and, finally, to the plans for future feedback (Tri-Council Policy Statement, 1998). Yet, according to the KORI Community Consultation Guidelines, when working with First Nations people there is also a need to seek the approval and negotiate the details of the research with the band council and relevant community organizations akin to the approval sought from educational boards. I therefore found myself in a dilemma because to be ethical in an Aboriginal context, elements of consent, recruitment and ownership need to be negotiated with the community as part of the research design. This requires contact with the community prior to formal approval granted by REB, which is generally prohibited. These concerns were discussed with the University of Guelph's REB and to my knowledge, for the first time in the history of the institution the board agreed that I could modify my research approach in accordance with the KORI Community Consultation Guidelines.

The next step was to submit a draft research proposal to KORI. Shortly after the submission, the proposal was returned to me from KORI as there were many modifications were needed. The first task was to make the language of the proposal and the questions for participants more culturally-appropriate. In terms of the written proposal, I was informed that the term 'Aboriginal people' should be spelt with a capital 'A' and while it is an acceptable term to use, it should be recognized that it is a collective term and often used improperly to impose a single identity on the many different communities. Second, the Aboriginal people generally prefer to be called by the language/cultural group or communities to which they belong. For example Aboriginal people inhabiting a large area from eastern Canada west to Alberta and the Great Slave Lake are known as *Cree* whereas those living west of Lake Huron in Michigan, Wisconsin Minnesota, Western Ontario and Manitoba with later migrations onto the northern Great Plains in North Dakota, Montana, and Saskatchewan, are known as *Ojibwa*. Third, the use of incorrect, inappropriate or dated terminology should be avoided as it can often give offense. Many historical terms or those in common usage some years ago are now not acceptable, including terms such as 'native' as well as terms such as 'half-caste' or any references to color or physical features as they do not signify Aboriginality and may cause offense.

In terms of the questions for participants, it was recommended that I use simple, 'present-oriented' terminology so that words could be easily translated into Cree. Cree significantly differs from English which is a 'future-oriented' language or a language that places emphasis on time and numeric order. There are also many words in English language, for example, the word 'researcher', that do not exist in the Cree language. Finding alternates for these words, for example 'outsider' instead of 'researcher', was also necessary.

In terms of the number and specificity of the questions, it was recommended that from the fifteen questions I had originally developed, I choose three for a community consultation (Refer to Table 3.1). KORI emphasized that participants would feel most comfortable if there were only a few open-ended questions so that they could speak at length in response, with the opportunity for anecdotes and examples. The three questions were developed in consultation with KORI and submitted for approval by the Chief and Council from Fort Severn.

The second task was to determine the procedures for obtaining both community and individual consent. As indicated in the KORI Community Consultation Guidelines, agreements about consent should be reached in accordance with acceptable local practice. According to the Fort Severn community, prior to contacting individual community members, the researcher requires consent from recognized community representatives. This is commonly done through the Chief and Council, the community's own internal procedures. The model used in the KORI guidelines includes obtaining community consent by creating a research agreement. This requires that researcher submitting a one-page summary outlining the purpose of the visit and the nature of the research which is then followed by feedback from the Chief and Council about modifications, additional considerations and a general approval or disapproval of the project. As recommended, a one page summary was submitted on behalf of KORI and the University of Guelph. Once feedback was provided, details of the research were re-negotiated and the necessary changes to the summary were made. Following, the approval, the project proposal was finalized and a completed research summary was re-submitted to the chief and council for future reference and proof of our agreement.

The Chief and Council then recommended a Community Contact (CC). The CC is a person from the community who oversees the research of interest. The CC is interested in how all

aspects of the research will affect the community. The CC will expect to be informed about the research methods to be employed during the study as well as the results of the visit and how the findings can be used to benefit the community. It was the CC who raised the issues of individual consent, recruitment of participants, data collection methods, ownership and dissemination.

In most research projects, informed individual consent for participants is usually obtained in writing. However, the CC informed us that for a variety of reasons (literacy rates, language barriers, etc), the community members would be reluctant to sign a written document. Thus, it was recommended that written consent be substituted with oral consent on the condition that a witness was present in all situations and that the consent form would be read to potential participants in an acceptable manner and language, and at a level and speed that permit comprehension. Clarification would be provided as needed and the participants would be informed that they would be able continue or end the consultation at any time and that they may agree or refuse to participate without penalty. A consent procedure meeting this criterion was developed and submitted for approval by the CCs. Once the consent procedure was approved, the CCs were encouraged by KORI to share it with potential participants prior to our arrival in the community (Appendix 2).

Issues pertaining to the recruitment of participants and the appropriate methods of community consultation entailed the assistance of a community-based researcher (CBR). The CBR is the link between the researcher and the community and is recommended by the CC. The CBR is paid by the researcher to complete the preparation work including planning and promoting the community meeting, setting-up meetings with elders, and serving as a translator during the consultations. The relationship with the CBR is essential to the success of the visit.

In consultation with the CBR and KORI, we developed a poster advertising a community gathering to discuss research in the community (Appendix 3). In accordance with local practices, the format of the meeting was determined to be a sharing circle (similar to a focus group). Permission to use audio or video-recording was denied to preserve the sanctity of a sharing circle as well as maintain the anonymity of the participants. As an alternative, summary notes would be made on a flip chart and verified by community members for accuracy following the interview. For those community members who could not leave their homes, the CBR would contact them by telephone and if willing, arrange a one-on-one meeting so they could express their views on the topic of interest as well. On completion of the sharing circle or one-on-one consultation, we would provide a small meal as well as small gift as appreciation for participation. It was suggested that we provide food items such as fruit and deli meats which where not readily available in the community.

This information was then presented to the CC. Once the posters and methods for consultation were approved, the CBR distributed and displayed the information throughout the community in areas such as the health centre, youth centre and grocery store as well as relayed the message through telephone. Special permission was also obtained from the CC to advertise the gathering on the community channel and the local radio station.

The last task was to negotiate the use of the results. It was agreed that the draft results would be reviewed by the CC as well as the relevant KO staff. Once the results are finalized, a clear, easy-to-read, accessible format of the results would be made available on-line. In addition, a hard copy of the thesis would remain at the band council office and the KORI office.

Once the details of the research were negotiated with the Fort Severn community and KORI, the information was submitted to the REB at the University of the Guelph for final

approval. The negotiated goals and objectives of the study were to identify key stakeholders perspectives (elders, community-based researchers, and non-First Nation researchers) about the means and conditions in partnership with the First Nations. These perspectives would then be drawn upon by KORI to modify their research consultation guidelines. Since this was the first time that the KORI Community Consultation Guidelines were being tested, it was also agreed that a staff member from KORI would accompany me to Fort Severn.

Methodological Background

Oral Tradition

Oral communication is valued greatly and widely used within First Nations communities. It is the primary method through which teaching and learning is carried out from one generation to the next (Einhorn, 2000). Oral tradition rests in the belief that information does not have to be written down to be true. Moreover, it is believed that writing absolves individuals from remembering and therefore, diminishes the complexity of knowledge retained in any society (Thorne, 1993). As Nobokov (2002) explains, "a people enrich their minds who keep their history on the leaves of memory (p. iv).

The lived experiences of the First Nation are tied to culture and oral tradition through narratives. These narratives embody practices and values, languages and laws, histories and family relations of its people as well as reinforce the inimitable communion they have with the Circle of Life (Einhorn, 2000). Knowledge embedded within the narratives is gained through observation, experience and practice and the narratives themselves provide the opportunity to reflect on issues of concern and depict the ethics that govern decision-making in the community (Vanderwerth, 1971).

Traditionally, community members sit in a circular format and oratories are conducted by an elder or a prominent person in the community. Methods of sharing knowledge include painting, carving, body movements and expressive dance (Vanderwerth, 1971). Today, oral traditions are also shared by the young and expressed through different methods including visual arts, drama, contemporary songs, and poetry. Oral histories can also be heard on the radio or seen on television, films and the internet (Einhorn, 2000).

Narratives as a Method of Inquiry

Narratives are messages that tell the particulars of an act or occurrence, or course of events, in a meaningful pattern. They reveal the way in which events and other actors can effect someone, provoking certain behaviors, shaping their possibilities and influencing the way they perceive themselves and the world (Mattingly, 1991) They also explore the complexities of body, environment and social contexts in determining a person's possibility for action (Mattingly, 1994).

Key to the structure of narratives is the integration of actions and events to form a plot. Central to the notion of a plot is time. Narratives possess a strong temporal component whereby the past shapes the present and the present guides future actions. Therefore, in narrative inquiry, actions and events revealed by the participants through narratives are sequenced and examined as a whole so as not to be regarded as a mere succession of independent occurrences but rather meaningful connections among incidences over time that contribute to a bigger picture or theme. The act of collecting and assembling these factors in a single story makes the plot a totality and through this, there is potential to understand the meaning of participant experiences (Ricouer, 1991).

In the research process, narrative inquiry serves a dual purpose. Narratives allow the researcher to become engaged in the narrative, with the opportunity to enter the minds of the characters and explore the deeper meaning of the narrative. The engagement factor is also related to the power of stories to stimulate an empathic response. It is the small details and the vivid images of human experience, unlike abstract generalizations or belief statements, that evoke a response which can help the researcher understand the complex and tacit meanings (including dilemmas, hopes and anxieties) that lie in the issue at hand (Frank, 1995; Kirsh, 1996). Simultaneously, the opportunity to share narratives invites individuals who are participants "in to the research process as people with a perspective and wisdom that are worthy of hearing" (Dutton 2003, 8). It creates a forum for new voices to be heard and guides the researcher in understanding life in a particular social system.

Research Participants

The first groups of stakeholders selected were elders and leaders. Elders and leaders were defined as Aboriginal persons who are respected and consulted due to their experience, wisdom, knowledge, and background. Identifying an individual in the community as an elder or a leader did not necessarily equate with age. For this stakeholder group, there were four participating elders and leaders from the Fort Severn First Nations community. The elders and leaders were selected by a community based researcher (discussed in the next section of this chapter), based on their availability as well as their interest and relevant knowledge and experience with the topic.

The second groups of stakeholders selected were community-based researchers. A Community based researcher was defined as Aboriginal persons in a community who are trained

to educate, problem-solve, guide, and interact on a day-to-day basis with researchers conducting studies within their community as well as in neighboring communities. For this stakeholder group, there were two participants who previously served as community-based researchers in Fort Severn.

The third groups of stakeholders selected were researchers. Researchers were defined as any non-Aboriginal persons who have worked in an Aboriginal community to discover, interpret or revise facts, events, behaviors or theories, or to make practical applications with the help of such facts, laws or theories. For this stakeholder group, there were six participants including consultants and researchers employed by Keewaytinook Okimakanak Research Institute (KORI) as well as faculty and staff from the Northern Ontario School of Medicine (NOSM). These institutions employ First Nations and non-First Nations academics/researchers, who work closely together, and whose primary purpose is to improve the quality of life for First Nations communities.

Data Collection Steps

Data collection was divided into three segments, each of which corresponded to a stakeholder group: elders and leaders, community based researchers and non-Aboriginal researchers. Data collection for this study involved a combination of individual and focus group interviews. The guiding questions with a list of corresponding methods are outlined in Table 3.1. The data collection process is described below.

Upon arrival to Fort Severn, the CBR escorted both the KORI staff member and I to the band office to introduce ourselves to the Chief and Council. A brief presentation on the purpose of my visit and the possible impact it would have on the community was carried out and all questions

and concerns about the study were addressed. The Chief and Council were appreciative that we had taken the necessary steps in contacting the community and requesting permission prior to the visit.

Following the meeting at the band office, the CBR took us on a tour of the community. We had the opportunity visits many service centers such the Health and Tele-health Centre, Community Hall, Youth Centre, Police Station, Youth Centre, Internet High School Building and E-Centre. This was an excellent opportunity to speak with community workers as well as see available resources for the community and get a general idea of how these resources are organized and managed.

Following the tour, two days were spent conducting individual interviews with elders. Meetings with the elders were prearranged by the CBR. Most elders prefer to speak in their native language of Cree, so the CBR also served as a translator. Before each interview, the research proposal was presented, verbal consent was obtained, and the option to withdraw from the study at any time was given.

In using narrative as a method of inquiry, it was my intention not to guide participants and allow them to tell their stories, and to encourage deeper levels of reflection and analysis without limiting or restricting their focus. I used a semi-structured interview format (Table 3.1). Although this approach required a greater length of time than a structured interview, it had the advantage of allowing participants to raise new issues and concerns that I had not thought of as a researcher. In most instances, the questions I asked arose directly from the information presented to me by the elders. This approach maximized each participant's control over their own story and prevented them from going in a direction that they might otherwise not intend or

wish. Following the interviews, the elders were presented with a small gift as a sign of respect and token of my appreciation for participating in the study.

A focus group, referred to as a sharing circle in the First Nations context, was held at the local school. The circle was conducted in a similar manner to the learning circle. Nabigon et al, (1998) used "learning" in their research as it is a process, which enables information-sharing, connections, and seeks balance and harmony. For Aboriginal people, sharing circles are traditional processes (related to the symbol of the sacred circle), which provide a safe place for participants to share thoughts and experiences on a particular theme (Hart 2002). The circle is an Aboriginal way of decision-making. While there is no limit to participants, ten to twenty is optimal (Hart 2002). For the circle I adhered to KORI's Community Consultation Guidelines.

The circle was opened with a prayer. Participants were also given the opportunity not to participate in the ceremony if they choose not to do so. Each person had the opportunity to speak and to be listened to without interruption. One question was presented to the group at a time and following the sequence of the circle, each person was given an opportunity to share their thoughts. Participant feedback was written on chart paper and re-presented at the end to the group for verification. Upon closing the circle a prayer was recited, gifts were offered to each participant and then there was a sharing of food.

The last part of data collection involved conducting semi-structured interviews by telephone and electronic mail, with non-Aboriginal researchers. The benefit of both telephone and electronic mail interviews is that they facilitated communication between individuals who were separated from me in both time and place thus allowing me to communicate with participants who otherwise, I would have been less likely to meet face-to-face because they are busy people. The disadvantage was that visual cues characterize most means of personal communication and

without the help of sight and body language I had to rely completely on what I heard. At the same time, there was some reluctance by participants to answer questions that were sensitive or complex in nature as they had never met me in person.

Methods

Table 3.1 outlines the methods used during each section of the research process. The guiding questions were developed in collaboration with KORI. Each set of questions are presented, along with the tool used to ask questions, as well as the participants involved in each activity.

Table 3.1: Research Methodology

Guiding Questions	Tools	Participants
What do you think of outsiders? What good experiences have you had with outsiders? What bad experiences have you had with outsiders? How do you think we can improve the way work with outsiders is done in the communities?	One-on-one interviews in person Sharing circle	Elders, community members, community workers
How can research be defined as "of interest" to First Nations people? How should priorities be established? What is the appropriate way to contact a community? How can one ensure inclusion of all parts of the community? Who should own the results of the research? How and in what form should research results be returned to a community? How can gaps in research be identified?	One-on-one interviews through electronic mail One-on-one interviews through telephones	Community-based researchers

Where in the First Nations have you conducted your research?	One-on-one interviews through electronic mail	Non-First Nation researcher
What attracts you to conducting research in the North?	One-on-one interviews through telephones	
What were the aims of your research?		
How did you go about achieving these aims? What methods did you use?		
Did you obtain community support for the project?		
Was there community involvement in the project?		
What was the outcome of your project?		
How did you present the results of your research?		
Did you obtain feedback from the community about your results?		
What made your experience positive?		
What made your experience negative?		

Trustworthiness

Validity is the evaluation of "trustworthiness" of the methods and analysis used, as well as the conclusions that are drawn (Pretty, 1994). This does not involve an acceptance of bias, or conscious attempts to prejudice data analysis to support a particular group or idea. Instead, it is the acknowledgement that theory is dependent on human understanding and interpretation of ideas, and that these vary both between groups and between individuals within groups. Pretty (1994) developed twelve trustworthiness criteria (Appendix 4) to determine whether a system of inquiry is methodologically sound; of which, four were used in my study. These include: triangulation by multiple sources, methods and investigators; participant checking; reports with

contextual descriptions and visualizations; and impact on stakeholders' capacity to know and act. For triangulation by multiple sources, methods and investigators, I conducted one-on-one interviews and focus groups with each of the stakeholder groups (elders/leaders, community-based researchers, and researchers) resulting in different perspectives about the same topic. For participant checking, after each interview or focus group, the data collected was verified for accuracy by each participant. For reports with contextual descriptions and visualizations, I kept a record of any observations or quotations capturing people's personal perspectives and experiences. For impact on stakeholders' capacity to know, this study directly increased awareness about the role that communities can have in the research process.

Data Analysis

The goal of narrative inquiry is to discover emerging themes from the narrative text during analysis. These themes articulate the fundamental nature of the lived experiences of participants. The description given by the themes provide insight and new understanding into everyday skills, practices, and experiences of the participants. It is the commonalities in the meaning, skills, practices and experiences that highlight particular events in a way in which they are not destroyed, distorted, de-contextualized, trivialized or sentimentalized (Benner, 1985). As a result, these accounts are effective strategies for portraying participants in a situation and for preserving meaning and context (Schwandt, 1994).

To analyze my data, narratives from each participant was entered into a spreadsheet. Each narrative was examined for particular themes and then grouped accordingly. Themes that emerged from the data collection include: (1) Research Councils and Funding Agencies; (2) Community contact and intermediaries; (3) Power and consent; (4) Ownership; (5) Positive

Outcomes; (6) Building relationships; (7) Research methods; and (8) Participation. From these themes, statements made by several participants were rephrased in the form of 'participants would find feature x helpful/unhelpful in context y' were made. These statements provided information on what improvements needed to be made in research procedures to reduce and possibly eliminate the chance of negative incidents occurring within communities in the future.

Summary

Intermediary organizations such as KORI specialize in communicating with First Nation communities and have experience in designing and delivering effective communication strategies to this population. They have links to the communities that can lend credibility and support to research endeavors. First Nations communities have different levels of awareness and understanding of issues that affect them; have different concerns and experiences of an issue than other Canadians; access information differently and have different sensitivities to issues. Therefore, the First Nation requires specific research activities that address their different information, program and service needs, use different strategies for delivering information, provide information in a form that is accessible and address any particular cultural sensitivities. The KORI Community Consultation Guidelines describe culturally appropriate practices for working with the First Nation while recognizing the need to adapt these guidelines to fit the research project.

Narrative as a method of inquiry for testing the KORI Community Consultation Guidelines and obtaining stakeholder perspectives on research, is compatible with First Nations peoples because it synchronous with their culture and values. As a research method, narrative inquiry assists First Nations people in recreating, through the oral tradition, features of the past,

present and future. The narrative process extracts significant implicit meaning of First Nations

culture and helps to capture the essence of key experiences and events in the community. A

product of the telling of narratives in this study is the capacity to reflect change that will improve

outside research in a holistic, ethical and culturally appropriate manner.

Chapter Four: Findings

This chapter is a report of the responses to questions asked in-person, electronic and telephone interviews as well as participant observation and sharing circles. The findings are organized into three sections, according to stakeholder group: consultations with elders/leaders from the Fort Severn community; consultations with First Nation community-based researchers; and consultation with non-First Nations researchers. Summaries of the issues raised by each group are presented under headings in their respective sections.

Consultation with Elders and Leaders from the Fort Severn Community

The following is a summary of the issues raised during consultations with the elders/leaders from the Fort Severn community.

Perceptions and Past Experiences with Research and Researchers

The twelve participants used the word *researcher* synonymously with anthropologists, consultants, educators, governments, health professionals, and scientists who are of non-First Nations origin. Only one participant indicated no previous contact with researchers. The other participants spoke about researchers with a high degree of frustration, disappointment and resentment.

One of the major concerns expressed by participants was the communication gap that exists between researchers and communities. This gap leaves the community feeling a sense of mistrust and most times, at a disadvantage. One participant said, "When these people [researchers] come into our community, the first things I think are what do they want from us now? And what's in it for us?"

The participants cited incidents occurring during home and school assessments. Most negative experiences occurred during health care assessments at local clinics and urban hospitals with non-First Nation health workers and professionals. Participants were most offended when researchers were acting unilaterally, paternalistically, and arrogantly in fashion or had financially driven interests in the community. As one participant recalled,

> I kept telling the doctor that my leg was hurting. He kept telling me there was nothing wrong with it. It was as if he was calling me a liar. Don't you think I know my body? How can someone else tell me whether or not I am feeling pain? Sometimes I feel that it is not even worth it to go to a doctor. When they don't listen, it's a waste of time.

Another participant added,

> I told the assessors that the mold had been growing in my house for over a year. They told me it's my fault because I don't clean my house properly. I clean my house everyday. Their advice was to clean more. Despite doing that, a year later, the mold has spread throughout the entire house and the whole thing had to be renovated. This could have been avoided had the assessors addressed the problem instead of laying the blame on me.

Rather, helping the community, as one participant explained,

> Means paying attention to the community's version of what they need rather than coming in and deciding what we need, telling us what do about it and how to go about doing it. It is about realizing that there are no easy, one-step solutions to problems, especially in our community. Researchers need to be aware of and respect the fact that we know what our problems are and that there are different ways of resolving issues, perhaps beyond the scope of how they resolve their own problems.

The participants also noted that most research conducted in communities has relied upon techniques and approaches that are intertwined with Western bias and scientific logic. These research models are ineffective because they dismiss the social and cultural complexities of First Nations communities. They overlook the dependency and responsibility associated with their small size.

As one participant said, "We belong to the community; it is our family. We look at this way because it is the only support system that we have. It is from the community that we discover ourselves, learn knowledge about the past and the present and learn how to use this knowledge to change the future."

Nonetheless, the participants emphasized that this does not mean that communities should prevent research from taking place or that researchers should be prohibited from coming into the community. They recognized that research is a valuable tool and it can highlight and develop solutions for many problems and concerns. One participant commented, "If done the right way, researchers can help obtain services and programs that we are lacking. They can help us to seek funds and help us write reports. If a researcher does it, maybe the right people will listen because they don't listen to us."

It became evident that most of the participant's apprehension does not lie in the research or the researchers but rather in the conduct of research and with regard to who the research benefits. To address this problem, participants emphasized that researchers need to avoid the temptation of launching programs and studies prior to establishing working relationships and agreements of understanding between themselves and the community. Many participants recommended a movement from project and production to process and participation. As stated by one participant, "If the research is going to benefit the community, then the community should help direct the work to meet their needs."

Ethics

Participants emphasized that the ethical behavior of many researchers need to be reconsidered. One participant said, "If we were respected, much of the research that is done in our communities would be unnecessary". Another participant commented, "Help from a researcher is too often help according to the researcher's agenda, not the community's agenda." Another participant added, "Unfortunately, a researcher's project often strays for what the community really wants and needs. This is because the researcher is controlled by someone else who they must be accountable to as well."

Participants agreed that researcher should realize that for the duration of the study, they are responsible to the community. Too often community members are submissive to the opinions as well as too accommodating to the preferences of researchers because they are considered to be the "experts". As a result, the research becomes more about the researcher rather than the needs of the community. As stated by one participant, "The researcher may be an expert in certain field but it is the community members who are experts on the community". Another participant expanded, "If a researcher would like to conduct a study, then it is the community that should have a say in what it wants from the work."

Some participants who had previously worked with researchers commented on an additional perspective to ethics. "Researchers must maintain a balance in everything they do." They emphasized that researchers should take a holistic approach to their work and they must respect those individuals who will be directly or indirectly affected by their work. One participant said, "The community may take a different view from the researchers about how research should be done. A good researcher will try to find a way to do the work in an acceptable way to everyone, not force something on them with which they disagree." All the

participants agreed that it is up to each individual or the parents of children, to consent to an interview on the basis of what he or she sees as the best interests for themselves, their family and their community. One participant added, "Researchers should also consult with women and children in the community because they are often left out of important decisions."

Research that is of Interest to Communities

Participants urged researchers to explain the usefulness of the proposed research to the community. Through understanding, as one participant explained, "The community can then become more involved by taking responsibility in understanding the problem and directing the research to find an appropriate solution." Another participant added, "When we understand what is going on and how it will help our community, then we are in a better position to guide the researcher on how to find information relevant to their study." Participants explained that the approach under which most research is undertaken is intrusive, so many communities reject projects for that reason alone. As one participant said, "We've been researched to death. Enough is enough." One way to enhance the community valuing and engaging in research is for the researcher to establish a long-term relationship with the community. This should include spending time in a community and participating in local activities for a period of time prior to the research project. As one participant explained,

> What bonds people in our community is our Aboriginal identity. So if you are not Aboriginal, it is important to take the time to get to know the community, build relationships, and respect people's experiences and what is important in their lives.

Another participant expanded,

> The best way to build relationships with the community is to visit the communities many times before actually conducting research. The community gets suspicious of researchers who show their face for one day and then leave the community. Sometimes these researchers don't even contact the band council; they just walk around, talk to people and knock on people's doors. By visiting the community ahead of time, it shows that there is a genuine interest in getting to know the community and what is important to them.

Furthermore, research also benefits the community when it is involved in the planning and execution of projects. This is critical considering that the records and results of a lot of research in the past were not the outcome of significant community involvement. Many times research material has not been looked at by the community and has not been accurately documented.

Research needs identified by First Nations communities includes alcohol abuse, education, low-income housing and health care. The most frequently mentioned issues were the cancellation of translators to accompany health care patients and the closure of educational facilities due to mold infestation. Research in these areas has been established as a priority and there is a need to clearly and publicly address the crisis in education and health care, and any research which helps to establish this need is welcomed by the community.

Building Trust

Since there has been a climate of distrust for researchers, it is important to establish a common ground to address issues that are important to the people. As one participant said, "the best way to build a relationship of trust in a community is for the researcher to be explicit about his/her intentions in the community. There is nothing more insulting than a researcher saying one thing but actually doing another, especially for his/her own benefit." Being honest and transparent

about the project from the beginning is a critical step in fostering trust and confidence with the community.

Once trust has been established, the researcher needs to learn more about the community. As one participant explained,

> It is important to read about the community, its history and the problems that have been going on. It is also important to verify this information because what is written in the literature is often incorrect. So the best way to learn about the community is to talk to the people about their experiences. It is the most accurate information you will get.

The First Nation is not just interested in the use of resources, but also a less materialistic approach to learning and sharing information. Participants indicated that culturally relevant activities that include social gatherings are the most effective methods of bringing First Nations people together for learning and sharing. Gatherings are based on understanding of spiritual connectedness and celebration. As one participant explained,

> They [researchers] should visit the youth at the youth centre, hold a community meeting for adults, and visit the homes of elders and just talk with them; not about their research though, just about daily life. They should share a meal with us, fish with us, hunt with us and through this find out how we are doing and what's important to us. This is how we bond with another in our community.

Efforts to create interactive methods of community research can significantly increase participation as people become more interested in getting involved when the initiative directly affects their lives.

Community Involvement

Participants agreed that research should be participatory. They defined participatory research as researchers providing participants with information on the project followed by a request for feedback. Participatory research they said, "Must involve First Nations people in all aspects of the research. It draws on the strengths of the people." Some participants recalled an example of

a successful participatory workshop on telecommunications held by Dr. Ricardo Ramirez and Dr. Richardson from the University of Guelph that was held in the winter of 1991. Those participants that attended the workshop said that they enjoyed the experience as it brought various sectors of the community together, it was culturally appropriate and it provided each person with an equal opportunity to share their visions and concerns.

Another participant said, "It is important to request feedback at two levels – with individuals and with groups because the answers to questions will depend on whether an individual or group is asked." This should be done constantly, periodically and systematically. The benefit of doing this, explained by another participant,

> Is that the people have knowledge about how the community works and how the community is working at that particular time. An outside researcher cannot know ahead of the time the problems of community life, the internal dynamics and the spirit of the community. With this knowledge, issues that are important to the people can be easily identified and addressed and done so in the right way.

To ensure meaningful involvement of the community, participants suggested the establishment of a formal arrangement in the form of a reference group, mentor arrangement, or a monitoring committee. This is important because although relationship building between researchers and First Nations people is growing, an interface is needed. A monitoring arrangement should be instituted at either local or regional levels depending on the scope of the project. Furthermore, researchers conducting a study in a local community should ensure the establishment of a monitoring committee. The committee would facilitate negotiations between the researchers and participants to protect the interests of all parties. The monitoring committee would also be used by the researcher for expressing, negotiating or resolving any problems or issues that may arise through the duration of the project including modification of intentions, methods, outcomes and form of dissemination. Such a forum would be a means of preventing

unintentional or inappropriate behavior by the researcher such as trespassing into restricted areas or events. Reports about the progress of the project should frequently be submitted to the monitoring community, which can then be responsible for making the results available to the entire community. It can also continue to serves as a point of reference for the researcher and the community after the formal conclusion of the project.

Initial Contact by Researchers

Participants explained that in most local First Nation communities, various organizations represent the community to varying degrees. These organizations include cultural centers, educational centers, health centers, band councils, legal aid centers, police services and women's centers. These organizations represent different interests in the community and in many instances, are in dispute with one another. Thus, many participants agreed that the primary contact for a researcher should be the Chief of the community. They felt that as a sign of respect, permission should be obtained from the Chief before any other acquaintances are made in community. Once permission is obtained, the type of research should determine which organization should be the secondary contact. The Chief can then direct the researcher to the appropriate contact at each organization. Following, the researcher should consult with and inform as many local organizations related to the research area as possible. In cases where the scope of research transcends local communities, umbrella or regional organizations must also be approached.

Nonetheless, some participants felt that approaching local or regional organizations is not always sufficient in gaining approval for a project. These participants felt that researchers

should consult with community members themselves in addition to the representative

organizations. As commented on by one participant,

> The researchers only value approval from the leaders. We understand this is
> necessary but the researcher also needs to seek approval to the entire community.
> Ultimately, we are the ones who will be affected by the decisions made by those
> leaders.

Another participant expanded, "The leaders often have a different way of thinking and so their

opinions may not be representative of the community."

Methods of Contacting Community Members for Consultation

Participants expressed that researchers should not approach community members without prior

arrangements and an introduction as this is considered unacceptable and can be unproductive.

As one participant recalled,

> They just knock on our door without any warning. Then they want to assess your
> house or ask you questions for hours. They forget that we have other things do to.
> If they just let us know of their visit earlier, we can prepare.

To address this issue, researchers should coordinate visits with community members at suitable

times on the advice of the relevant organizations.

Another form of community consultation suggested for researchers by participants is a

community meeting to introduce themselves and the research project to a wider community.

However, these community meetings need to be largely advertised to maximize consultation and

participation. As one participant commented,

> Many times we are interested in projects that are happening in our community but
> we don't know anything about them. By the time we become aware of them, the
> researchers have already come and gone and not heard what we have to say.

One method of advertisement agreed on by all participants was the community channel on the

radio and television.

Consultation with Community Members Following the Completion of a Study

Participants stressed the need for researchers to make visits to the community following the completion of the study because they feel that initial consultation does not exclude the requirement for continuous development of relationships with community members. As one participant explained,

> A researcher comes to our community, takes the information they need and then is never to be seen again. What happens to us? What happens to the information we have given them? We have a right to know.

Thus, researchers should maintain an enduring relationship with the community. As one participant noted, "accountability is an integral part of community development and listening." Even if the researcher is unable to return to the community, a relationship can be maintained through videoconference, email or telephone. This ensures that the research study does not constitute a breach of trust or cause embarrassment. It also regulates the dissemination of any information that may disadvantage the community or which may have become sensitive because the situation has changed. While some members of the community may feel the need for a formal agreement, developing trust through personal relationships is also necessary.

Feedback of Research Outcomes to the Community

Most often, the final results of a research project are compiled following the departure of a researcher from the field without community revision. This is of concern to the community as researchers have the indisputable right of academic freedom to research and publish. Participants stressed that prior to the finalization of the research product, community members should have the opportunity to review and discuss the results. As one participant highlighted, "results of the work are likely to be useless if active feedback is not an ongoing part of the

work". The researcher can present draft results in a community workshop prior to departure or budget for a return visit to the community. This way, the community has a forum to correct any misinformation, add to missing information, provide additional comments and it also allow for the community to feel engaged in the research process right to the end.

In addition to the formal results of the research, participants would like to see a summary of the final outcomes created for the community in an appropriate and accessible form. Written material should be presented in both English and the Native language, and audio-visual format is often preferable to written presentation. If a return visit is feasible to present draft results, the final results should be relayed through videoconference.

Participants also requested that during the initial stages of the project, researchers should negotiate with the community on the place where research results will be kept. Participants would like to see the results in a location that is easily accessible to all community members such as at the Band Council Office as well as in a location where results can be kept for long-term management such as KORI. It is also critical that the researcher return research results to individuals who have played a significant role in the project and to organizations that can directly benefit from it. This can be done in a written report format or verbally communicated in person or through video-conference.

Community-Based Researchers (CBRs)

The following is a summary of the issues raised during consultations with community CBRs.

Initial Contact

When the researcher would like to conduct a study in a small community or group, the CBRs suggested that permission should be obtained from the community. When the study involves a larger community or group, it is critical that the permission be sought from the appropriate elders and community administrators. Most disrespectful, as one CBR explained, is when, "researchers ask for approval for a proposed research and then go ahead with the project despite community disapproval."

The CBRs suggested that new researchers should seek the assistance and advice of an established researcher in the community where they propose to conduct their research. This person will be essential in acting as an intermediary with the community, playing the role of a "central information-gathering and sharing agent". Ideally, such intermediaries should be working for a First Nations organization. For example, CBR's act as KORI representatives on-site.

Prior to the commencing the research, it is vital for the researcher to visit the community where the research is to be carried out. Although the Chief and Council does not always represent the entire community, spending time in the community to discuss research with them prior to the fieldwork provides reassurance of sufficient consultation than if no visit occurred. As stated by one CBR, "Visiting the community provides the opportunity for developing a mutually effective process and to identify any drawbacks prior to commencing the project." Another CBR added, "It allows communities and researchers to decide what can be done with existing resources and determine what is required from outside sources." While planning the community consultation, the researchers should also plan the logistics of accommodations, provisions and transportation.

While visiting the community, negotiations between communities and the researchers about ownership, dissemination and uses of data should take place in the form of a contract. In addition, negotiations should also be made about the allocation of rights over the research results, the rights of the community and of the researchers as well as of the sponsoring research organization. The CBRs stressed that in all cases, the community has the right to be fully informed about the proposed research, including its purpose, potential impact, and form of dissemination as well as the level of intrusion this will have on the lifestyle of the community. As one CBR stated, "Often, community concerns and desires do not coincide with the research objectives." The other CBR expanded, "If the community cannot see the benefit from the research, the community will not allow the research to take place."

The CBRs revealed that community approval usually depends on the nature and scope of the research project. The nature and scope determines from whom approval should be obtained. For example, if the research is to be conducted in a local community, approval can be sought through a local representative body following a presentation of the research at a community meeting. If the scope of the research is at a national level, approval could be obtained by an organizational structure of the national most relevant to the research and this would most likely be done in writing.

The CBRs stated that in cases where funding is sought by the researcher, the community's' decision should be based on a perceived need for the research. This allows the local communities and organizations to have greater power and control over the research process. One CBR explained,

> In this case, it would also be helpful for the community to have a manual with a description of eligible projects and funding organizations so they can make an informed decision as to whether or not the research is needed. They should also

receive guidelines to determine appropriate roles and responsibilities of everyone involved in the research.

The problem arises when the funding is provided by outside sources. As one CBR explained,

> This is when the community feels powerless in the research process because they are not the ones paying for it. The community needs to be empowered; they need to realize that they can have control over researchers that come to the community and that they can have ownership of the results.

The CBRs stated that First Nations communities and organizations aspire to have more control over the dissemination of research results, including the format in which it is presented. Material can be presented in English, native language, verbally or audio-visually. They suggested that the dissemination of results would need to include one or more of these formats to meet the needs the needs of varying audiences.

Community Involvement in the Execution of Research Projects

The CBRs stressed that all research of interest to First Nations should include community involvement at all stages of the study. As one CBR highlighted,

> Community development starts with a researcher who has a balanced look at the community and its people. From that balanced view, the community becomes included in articulating the vision of what might be.

The project should be a partnership between the researcher and the community. As one CBR explained,

> Partnership is not about telling them what to do. It is a process of providing new opportunities, breaking down barriers, of advocating, of being proactive, of connecting people with information, expertise and ideas.

One way of ensuring effective involvement is to launch a training program for community researchers. As one CBR commented, "Research process can be confusing and

overwhelming to communities." When community members become familiar with the research process, even in the absence of extensive experience, benefits can accrue for both the researcher and the community. Community researchers can act as guides and play a role in gathering and analyzing data as well as implementing outcomes in the community after the formal conclusion of the study. Ideally, First Nation education providers should carry out training however this type of initiative would require funding. As one CBR highlighted, "There is a need for local control, decision-making ownership and participation." Training community members at a tertiary level will allow them to facilitate their own research, thus providing them with more power and control over the research process.

Lastly, the CBRs stated that to facilitate productive research, community involvement should be accounted for during the formulation of aims and methods of a study. It is also vital that that research priorities be discussed with the community because if the topic seems irrelevant, involvement might be limited. It is also important for the methodology to include customary methods of discourse. For example, as one CBR stated,

> Viewing a site with community members is more interactive and productive than just hearing about it. If you can get elders, adults and children involved, then this kind of visit can also provide an opportunity for younger members to learn traditional knowledge about the site from the elders, thus serving a community purpose at the same time.

In addition to allowing for community participation in the aims and methods of a project, community involvement should also be considered in the presentation of outcomes. For example, whether community members would like information presented audio-visually, verbally, in writing or posted online (as negotiated in the case of this study). This should be discussed while the researcher is in the community. In fact, to facilitate more effective

community engagement, the researcher is encouraged to institute an advisory group, which should operate in compliance with community methods of communication.

Non-First Nation Researchers

The following is a summary of the issues raised during the consultations with Non-First Nations researchers.

Reasons for Conducting Research in the North

Researchers indicated that a majority of research has been initiated from within the academic community or non-First Nations organizations. This includes research formerly done in the same subject area (for example, a continuation of post-graduate studies), research conducted in related areas, cross-disciplinary research (for example, research in another health area), and research generated by theoretical interests within a discipline (several educational projects). A small number of projects were either community driven or initiated as a result of negotiations between non-First Nation researchers or a First Nation community (for example, the Tele-health program). The aims of the research projects included communication development, establishing educational programs, health care evaluation and improving the delivery of medical and dental services.

Research Methods

Researchers indicated that while conducting research in First Nations communities, they used methods such as questionnaires and interviews, documentary research with analyzing and recording being the most common. Many of the methods identified are strongly entrenched in

particular disciplines for example, participant observation (e.g., social science), documentary research (e.g., history), surveys (e.g., education), recording and analysis (e.g., environmental science). Only a few researchers indicated that they employed methods, which involved community members in active and significant ways, such as workshops, community or elder consultations, and participatory action research.

Community Involvement in the Research Project

Only one project, in the area of information and communication technologies, conducted by non-First Nations researchers, was initiated by First Nations organizations. Two projects, in the area of medicine, obtained no community support (including informing First Nation organizations). Three projects, one in the area of dental care and two in the area of education, received community support in some form, even if it was only through contact from a local organization. Most researchers did not visit the community prior to commencing the study unless they had been there in the past for another project.

With respect to community engagement, a majority of researchers indicated that there was First Nations involvement of some degree. Most researchers obtained First Nations participation through community workshops during the data collection phase or as a means of obtaining input on draft results. Only a few researchers employed community members as a primary researchers, co-researcher or supervisor.

Feedback of Research Results

Most researchers indicated that First Nations feedback was not specifically planned or facilitated in the community. For those few projects that did incorporate community feedback,

the processes were diverse. Methods of obtaining feedback included website postings, videoconferencing, workshops for communities and local organizations, and return visits to the community, and continuing involvement in the community.

Concerns

Many researchers commented on the difficulty of gaining community support on research projects, especially from the leaders, because First Nations communities are not homogeneous. The complexity arises in trying to identify all the individuals in a community who may have an interest in the project. In addition, researchers find it challenging to consult a community at a distance. For example, isolated communities may not have phones or faxes and literacy and language barriers make be too limited for effective communication by letter. Nonetheless, researchers emphasized that a community visit can make a difference. They have found that many community members are approachable, interested and willing to be involved during a community visit. This was corroborated by the fact that most researchers had no difficulty recruiting community members to participate or assist with research projects.

Other issues raised by researchers, including myself, were the concept of time and lack of funding. Of particular concern is the time needed to facilitate communication in a context where the researcher does not speak the native language; and more time requires more funding. These issues usually arise with projects sponsored by a non-First Nation research organization or in academic disciplines, which do not have significant involvement in research of interest to First Nations people.

Another issue mentioned by researchers was the ownership of research results. When a researcher is sponsored by a First Nations organization, ownership is perhaps more clear-cut than

when research is funded by a research body that is non-First Nation. A related issue is authorized access to research results, mainly written and audio-visual records. The First Nation often feels that there is no culturally sanctioned authorization to permit access to and use of such material by researchers.

In terms of returning research results, the only issue raised was the lack of central repositories where results of research could be returned to communities.

Summary

Responses to the in-person, electronic and telephone interviews as well as participant observation and sharing circles, revealed that most research of interest to First Nations people excludes community involvement from the planning process to the analysis of the final research results. Most of the research projects were initiated from the non-First Nations organizations and institutions and reflected the interests of those concerned rather than the community. This was particularly evident in the methods adopted, most of which were strongly rooted in the nature of the disciplines or goals of the organization. Most outcomes were conventional products including articles, books, theses and reports. In most cases, community feedback was not planned or facilitated by the researcher. It is evident that most researchers still operate in a mode that does not allow for real community input in the research process.

From elder/leader and community-based researcher consultation, the emphasis was on the gap between the research being conducted and the needs of the community. The general consensus was that there needs to be an adequate level of support for projects of interest to First Nations people and that there needs to be community involvement at all stages. This requires numerous changes in research methodologies, from having communities decide which research

projects should be undertaken to reporting research in a way that is accessible to communities, even if it is not in a traditional academic format.

In response, researchers expressed the challenges of consulting with communities at a distance. They recognized that, to avoid misunderstandings, in-depth community consultation is necessary before the commencement of a project and that there is no substitute for a community visit. They emphasized that more time is needed to develop personal relationships during the conduct of the research and that there is a need for funding and research organizations to recognize and accommodate for this.

The main issue that arises from stakeholder responses is the effects of insider-outsider interactions. Community engagement in the research process is a direct means of raising people's consciousness of important issues in the community. However, to effectively achieve this, a researcher must find a means of communicating with the members to foster a maximum level of understanding. As demonstrated in stakeholder responses, this is seldom achieved as the actual communication on the insider or local side is still one-sided; the approaches, concepts and language that are used are always more heavily weighted on the side of the outsider. It is evident that the reality of the community's situation and its inherent problems can only really be known from an insider's perspective and that the situation needs to be expressed in insider's language. Thus, the outsider must diminish his or her role as the expert and extractor of information and consider taking on the role of a facilitator. Facilitating community engagement includes putting systems in place to create and sustain the knowledge, skills and attitudes needed for nurturing existing capabilities and empowering people. This will provide the community with a positive feeling, creative inspiration and confidence about their development and their formative role in it.

Chapter Five: Discussion

The objectives of this research study were to gather stakeholder perspectives (community members, community-based researchers and non-Aboriginal researchers) on challenges, concerns and visions for developing a collaborative research process in the North. Chapter Three outlined the methodology used to obtain these responses from stakeholders. Stakeholder perspectives were then reported in Chapter Four. This chapter discusses the themes that were emergent from the literature and the findings. This chapter is divided into eight sections; one for each of the themes identified as a factor in developing a collaborative research process in the North: Research Councils and Funding Agencies; Community contact and intermediaries; Power and consent; Ownership; Positive Outcomes; Building relationships; Research methods; and Participation. The chapter concludes with a discussion of Ownership, Control, Access and Possession (OCAP), which connects the themes from the literature and the findings.

Research Councils and Funding Agencies

The consultations with community members and community-based researchers reported in Chapter Four suggested that the behavior of researchers working with First Nation communities has not been sensitive to the First Nation values and interests. Issues such as exploitation, community damage and inaccurate findings have been identified as major concerns among all of the community members and community-based researchers interviewed. This has been in part attributed to the research culture which is bound by limitations of time and funding.

In Canada, research ethics in universities and publicly funded research institutes are guided by the Tri-Council Policy Statement (TCPS), adopted jointly by the major research granting councils: the Natural Sciences and Engineering Research Council (NSERC), Social Sciences and Humanities Research Council (SSHRC), and Canadian Institutes of Heath Research

(CIHR), formally the Medical Research Council. The three councils receive funding from the federal government for distribution to research bodies across Canada. Current ethical guidelines and the governance structures through which funding is administered need to be reviewed because of a number of shortcomings identified by the researchers and community members interviewed (Medical Research Council et al., 1998).

One of the problems identified by two researchers interviewed is the competition for allocated funding from the government and industry. As a researcher myself, who has had experience with applying for funding from various agencies, I find it not surprising that researchers often misrepresent the context of the situation: "in an effort to secure grants for research or for services and programs, writers are driven towards magnifying and dramatizing the problems of the of the local community" (Wax, 1991, p.433). Furthermore, consistent with the literature review, one researcher explained that the production of immediate research outcomes mandated by the structure of year-to-year funding of research councils does not account for the longer periods of time required for developing community-researcher partnerships in the First Nation. Limited funding and a haste to complete project deliverables on time compel researchers to focus on predictable results expected from the outside that rarely advance the state of local knowledge, programs or services. One community-based researcher stated that academic institutions and funding agencies could address this issue by necessitating that researchers include capacity building, empowerment and self-advocacy as part of their research objectives.

The SSHRC attempted to address this problem by creating funding through the Community-University Research Alliance (CURA) Program. Community-university research

alliance is based on equal partnership between an organization from the community and university. The purpose of the program is to support the establishment of community-university alliances which through a process of ongoing collaboration and mutual learning, aims to foster innovative research, training and the creation of new knowledge in areas of importance to the community. It should be noted however that CURA is not aimed specifically at Aboriginal contexts. The experiences of one researcher who applied for CURA funding stated that although partner organizations are involved in the process, community members, or at the very least community leadership, were never consulted for building the research proposal.

Lastly, it is important to discuss the issue of context with respect to developing polices and programs. Initially, this study was to take place in three communities: Deer Lake, Keewaywin and Fort Severn. Due to a high cost of travel and the new costs associated with the KORI Community Consultation Guidelines, the research became limited to a single case-based study in Fort Severn. Although case-based research can lay the foundation for generalizing some common principles across contexts, this requires conducting a cross-analysis which was not possible under these circumstances.

The cost of ethical and culturally responsive research in the North is high and rising and this has the potential to deter many researchers. Existing grants do not cover the additional costs of conducting research in the North. For example, the research funding obtained for this study failed to take in to account the high costs associated with licensing, traveling to remote fly-in communities with uncompetitive airfares, and the process required to negotiate research agreements such as employing an intermediary organization like as KORI. These expenses were deducted from funding that should have been used to spend time and establish a long-term

relationship with the community through cultural encounters. As highlighted in the conceptual framework, both granting and research councils need to understand that establishing relationships and ground rules for research in the First Nation requires valuing differences as well as an investment of time and effort to consult with all the relevant sectors of the community prior to finalizing a research proposal. It also requires a certain level of cultural self-awareness, knowledge, and skills as well as genuine caring and concern for the community on the part of the researcher. Thus, there needs to be more time and funding allocated for meaningful engagement with the community rather than a budget that allows for the involvement of one organization to make decisions on their behalf without being consulted.

Community Contacts and Intermediaries

The community members and community-based researchers interviewed indicated that researchers are required to speak with community representatives and seek approval prior to undertaking any fieldwork. Among the First Nation, however, there is hardly a more complex area than community representation. Representation is multifaceted; it is dependent on genealogical and land–based relations; it is linked to principles of identity and land ownership; it is about defining who is the politically responsible group in any particular situation; it is about traditional authority in both sacred and secular arena as far as these are conceptually separable; and it is a highly personalized processes of decision-making. Thus, the task for any researcher is to obtain consent specifically for each research project. This involves making an assessment about who constitutes the appropriate persons or organizations to contact, consult with and provide such consent.

In the First Nation, the Chief and Council (members of which are referred to as community contacts (CCs) in the KORI Community Consultation Guidelines) have been

identified by the community members interviewed, as the culturally appropriate authority to act as spokespersons for the community and as a point of reference to initiate the consultative process. However, given the diversity of people and interests, over time, it became apparent that Chief and Council do not always represent the community research needs adequately. In fact, many community members interviewed agreed that there were many small cooperatives and organizations that could have provided more accurate representation of a community perspective, but there were limitations to the extent to which they wished to be involved or were able to become involved as a result of community power dynamics. Any activity within the community must be done at the discretion of the Chief and Council regardless of whether the community-based organizations agree with them or not; thus, the Chief and Council are currently the only practical means available for initiating contact and obtaining approval for research within the community.

Three community members and both community-based researchers interviewed also indicated a need for a monitoring committee to facilitate the research process between researchers and communities. This suggests a need for what anthropologist's term, a *cultural broker*. A cultural broker is a middle-person who bridges, links or mediates between groups or persons from diverse groups, in order to reduce conflict or produce change, without compromising the integrity of any. The broker comprehends the relevant cultural systems, is able to interpret cultural symbols from one frame of reference to another, can reconcile cultural incompatibilities, and recognizes how to establish linkages across cultures that facilitate the research process. This individual is able to facilitate the process as they have frequent contact with the community and are aware of their socially and culturally based needs (Geertz, 1960).

The relative powerlessness of the community in the research process is an underlying cause for establishing the brokering process on their behalf. The degree of power that brokers could exert outside the community also affected the brokering process. Thus, depending on the influence they have, cultural brokers can become power brokers as well. For example, Aboriginal nurses, teachers and social workers (who are often employed as community-based researchers (CBRs) as outlined in the KORI Community Consultation Guidelines) act as cultural representatives of the health care system, education system and the government respectively, and as such, possess a degree of power to negotiate effective research, programs and services for the community. However, this influence is dependent upon the power they hold within a particular system, on skill and personal influence, and on their commitment to speak on behalf of those who cannot circumvent the barriers that are present as a result of powerlessness.

One of the challenges that I encountered as an outside researcher (as did the other researchers interviewed in this study) was that the Fort Severn community did not have a formal network to facilitate the brokering process. Instead, the group of leaders that formed the Band Council, who were previously identified as the initial contact for researchers, also appeared to be the only interface available. In response, for this study, we tested the role of KORI as a formal network in the brokering process. Although KORI is not a grassroots organization, it has previous ties to the communities which lends to credibility and allows them to employ CBRs (also trusted by the leadership) for on-site representation.

Speaking with community members and community-based researchers, and after going through the research process myself, it became apparent that utilizing an organization such as KORI to negotiate the research process can have distinct advantages over time, relative to solely relying on a community-based organization such as the Band Council. It is important to

recognize that members of the Band Council can change during the course of a project, which can adversely affect the research it is operating through the council. For example, if a project is strongly identified as being supported by the previous leaders, the incoming representatives may not allow the project to evolve. Several community members interviewed agreed that by keeping projects independent of politics, even if administrations or policies change, there is less of a chance for projects to be adversely affected or terminated. Furthermore, the community members interviewed stated that in cases where information is very personal and sensitive in nature, this independence provides them with and sense of confidence and security as well as an added assurance of confidentiality. This was the stated response to a number of incidents where certain leaders in the community inadvertently violated privacy rights. However, as discussed in the first section of this chapter, a researcher will have to assess the costs and benefits of employing members of an intermediary organization based on the amount of funding obtained for the project; nonetheless, from a community perspective, an intermediary organization is essential.

All of the community members and community-based researchers interviewed agreed that community-researcher interactions remain a key variable for cross-cultural research. As highlighted in the literature review, greater social and cultural awareness and sensitivity on the part of the researcher is needed and this can be accomplished with a cultural broker. The use of a cultural broker such as KORI provides the community with advocates in systems with barriers that are difficult or impossible to overcome. It ensures that researchers are aware of and sensitive to community's culture and needs as well to the political and social structural contingencies that will facilitate or impede the research.

Power and Consent

All but one of the community members interviewed provided examples of researchers acting unilaterally, paternalistically and arrogantly. Examples in the literature as well as the quotations highlighted in Chapter Four suggest that there are power imbalances that exist between the researchers and participants. Power is a key underlying issue when conducting research with marginalized and minority populations. As the literature review revealed, research with Aboriginal populations has often reflected a power imbalance that is rooted in colonialism. The community members and community-based researchers indicated that power imbalances could be less problematic if researchers were to integrate within the community rather than enter as an expert. Developing partnerships with research participants and defining ethical and unethical behavior jointly may reduce the risk of unintentional insensitive action or treatment.

One community member interviewed stated that concerns about power also focus on informed consent. Consent is informed when:

> It is given by a person who understands the purpose and nature of the study, what participation in the study requires a person to do and to risk, and what benefits are intended to result from the study (Council for International Organizations in Medicine, 1995, p.247).

Many community members agreed with the above comment by stating that researchers were not informing the community about their research and not obtaining the appropriate approval from leaders to collect data from community members. However, one community-based researcher agreed that given the option, the community might not always possess the information, knowledge or understanding of the concept of informed consent to make sound ethical decisions, which the researcher may be ethically bound to consider.

Some community members interviewed also indicated that researchers were not obtaining individual consent from participants prior to conducting interviews. Obtaining

individual consent in Aboriginal communities, as alluded to by the community-based researchers interviewed, is inherently problematic. Henderson (1996) explains, "No single individual can ever be aware of all the cultural concerns that may exist in the community" (p.83). These concerns, in part, pertain to the public disclosure of certain information, such as the location of sacred places or rare species, knowledge on traditional medicines or insights of a personal nature, which would be considered treacherous to families and communities. Securing sensitive information requires that the communities, where possible, develop the capacity to ensure its protection and that the holders of that information are respected. Furthermore, the Tri-Council Policy Statement (Medical Research Council et al.,1998) leaves open the question of when individuals may be interviewed without regard to the group as a whole, without seeking permission from any group authority or representative. Therefore, in the case where the community decides that it is appropriate to disclose protected information, they should do so on terms and conditions that ensure their own values are not compromised and benefits gained are consistent with their needs. This challenge is further elaborated below.

To understand the nature of the dilemma, it is important to recognize that notions of collectivity in Aboriginal culture contrast with the Western paradigm of individual consent. Linda Smith (1999) explains:

> 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 informed consent. The social 'good' against which ethical standards are determined is based on the same beliefs about the individual and individual property (p.11)

Given that Aboriginal knowledge is collectively owned, the community members interviewed stated that only the community can give consent to its sharing. As Daes (1993, 9) explains:

> Heritage can never be alienated, surrendered or sold, except for conditional use. Sharing therefore creates a relationship between the givers and receivers of knowledge. The givers retain the authority to ensure that knowledge is used properly and the receivers continue to recognize and repay the gift.

Since communities also experience internal conflicts, divisions and differences, representation would be elusive. Therefore, at the very least, permission should be obtained by researchers from the Chief and Council before undertaking any research endeavor. Then if possible, consent should be obtained from relevant stakeholders by sectors and then from individuals. However, it is rare that researchers will have enough time or funding to do this in the initial stages of planning research. Thus, it is critical that the definition and source of informed consent for participants in the First Nation be clearly and operationally defined and this should be done on a case-by-case basis.

The KORI Community Consultation Guidelines addresses this challenge in that it requires the researcher to negotiate the process of consent with community leaders according to local practices defined by the Chief and Council. In the case of this study, an oral consent procedure was negotiated due to the fact that community members would be reluctant to sign a written document. The leaders of the community also insisted that with this oral consent procedure there be a witness [community-based researcher (CBR)] present in all situations and that the consent form be read to potential participants in an acceptable manner and language, and at a level and speed that permit comprehension. Clarification would be provided as needed and the participants were informed that they could continue or withdraw from the interview at any

time. The research did not commence until this procedure was approved by the community contact (CC).

Many researchers working with the First Nation do not negotiate a process of consent as outlined above with communities. This is because researchers (as I did myself) find themselves in an ethical dilemma because to be ethical in an Aboriginal context, elements of consent should be negotiated with the community as part of the research design. This requires contact with the community prior to formal consent being granted by the Research Ethics Board (REB), which is often discouraged. These concerns need to be discussed with the REB so that modified approaches to research can be negotiated and the violation of both Aboriginal and institutional ethics can be prevented. In the case of this study, concerns about consent were discussed with the University of Guelph REB and the board agreed that I could modify my procedures to reflect those recommended as culturally appropriate by the KORI consultation guidelines.

Both the community-based researchers and most community members interviewed also demonstrated concern that researchers compile, summarize and publish data without feedback and permission from the community. This was supported by the fact that most researchers interviewed indicated that feedback from the community was not specifically planned or facilitated in any stage of the research process. Many authors, particularly those who advocate participatory research, argue that informed consent from the community is an on-going process rather than a one-time formality. Piquemal (2001) suggests four recommendations to ensure informed consent is appropriately obtained and maintained in Aboriginal settings: (a) Negotiating responsibilities prior to seeking free and informed consent; (b) Obtaining free and informed consent from the relevant authorities, the collective and the individual; (c) Confirming consent and ensuring that consent is ongoing; and (d) Providing the community with data for

feedback.   The community-based researchers agreed that this process of negotiation and renegotiation serves to facilitate true collaboration by creating a forum through which all stakeholders have an input in the research process.

Ownership

Both of the community-based researchers interviewed identified the lack of ownership of research data as a major concern. All of the researchers interviewed also agreed that ownership is a complex issue. They indicated that when research is sponsored by a First Nations organization, ownership is more clear-cut than when research is funded by a research body that is non-First Nation. In situations where ownership was unclear, the researchers assumed control of the data.

To address this matter, it is important to discuss the deficiencies in typical academic models of research where only the researchers assume ownership of the data. First, the general public or service providers, particularly in an Aboriginal setting, are not likely to be exposed to findings that are only published as articles in academic journals. Second, if non-academics read a journal article, the implications for practice or change may not be obvious to them and misinterpretations may occur. Thus, conclusions derived from the research needs to be translated for comprehension in a societal context and should be made in the form of a pamphlet or community presentation in-person or through videoconference. Third, if other academics, policy-makers or service providers do read an article containing research findings, do recognize a need for change, and actually execute a practice or policy change on the basis of the research, this might occur without the researcher's or the community's knowledge. Thus, both community-based researchers interviewed suggested that through the sharing of data and results could avoid many ethical problems in the First Nation context and would increase ownership by

the participants. For example, the KORI Community Consultation Guidelines recommend that when the study has been completed and analyzed, the community and individuals in whose domain the research was conducted should be informed of the findings and conclusions in a clear and comprehensible manner, and materials collected during the course of the research should be returned to the community. This includes that the final product be deposited in its collections, that means be adopted to protect these from improper access and use, and that arrangements be made in collaboration with community representatives for publication of the research results. However, negotiating the storage and management of raw data was not specified in the guidelines and was therefore not discussed with the community.

In the case of this study, it was agreed that the CC as well as the relevant KO staff would review the findings. Once the findings were reviewed, a follow-up with the community would be done on videoconference and a clear, easy-to-read, accessible format of the results would be made available on-line. In addition, a hard copy of the thesis would remain at the band council office and the KORI office. Most researchers interviewed would likely be willing to comply with such requirements and requests but agreed that one challenge might be the possibility that they may compromise their own intellectual property rights in the resulting research reports. The three national granting councils also debated the issue of collective rights and consent in the formation of the TCPS in 1998. However, it was decided that the council would not take a definitive position. Rather, there is a preface to Section 6 of the TCPS (1998) providing best practices for conducting research in Aboriginal research. Section 6 of the TCPS (1998), Research Involving Aboriginal Peoples, recommends:

> When research involves Aboriginal individuals, researchers and REBs [research ethics boards] should consider the interests of the Aboriginal group, when any of the following considerations applies:

a) Property or private information belonging to the group as a whole is studied or used
b) Leaders of the group are involved in the identification of potential participants
c) The research is designed to analyze or describe characteristics of the group
d) Individuals are selected to speak on behalf of, or otherwise represent, the group

The TCPS (1998) still provides no guidance on the issue of collective ownership thus leaving the issue open for discussion. Nonetheless, there was a statement following Section 6 indicating that the best practices are only cited as guidelines and that final standards should be developed (at the discretion of) REBs in consultation with Aboriginal communities. Most university REBs (because they are given the choice) are not willing to let researchers give up ownership of data to the communities. In addition, a standard item that remains in many ethics protocols is a declared intention to destroy the data after a specified number of years following the end of the project funding period. Many community members interviewed stressed that by discarding data collected from research projects, there is a risk that valuable information, such as the elder's testimonials, might be lost and unheard by generations to follow. Once again, this is an issue that must be discussed with the REB. The REB could, however, accept the requirement that they negotiate the public use of data. A written contract in which the details of the community's and the researcher's concerns about the appropriate use of research results and/or publication of material could be specified and subjected to arbitration if necessary.

Building Relationships

All of the community members and the community-based researchers interviewed highlighted the importance of building relationship with communities and to allocate the time required to do so. The responses reported in Chapter Four stressed the importance for researchers to establish

and maintain a secure interpersonal relationship, as the basis for any research project. The terms 'trust' and 'relationship' were frequently used in quotations from community members and community-based researchers. From this relationship of trust would follow an agreement by, and desire of, the community to share access to information and to places. This would also include a desire by the researcher to respect the community's wishes about limitations on access, confidentiality of information, and the provision of results in the appropriate forms

The issue being discussed above is one of transparency. Researchers must decide the extent to which they will ensure that the objectives, methods and impacts of their research are made transparent to the participants. However, this requires weighing both the costs and benefits of being open. On the surface, it seems to be simply a matter of distinguishing between what is overt and covert. Overt research decisions encompass full and open disclosure whereas covert decisions are based on partial disclosure. However, some of the researchers interviewed indicated that decisions about what type of research to carry out often remain unclear until the researcher is in the field. As Punch (1986) explains, the overt-covert distinction is a continuum rather than a black and white scenario. This is and will continue to be the case as qualitative methods move beyond the scope of the traditional 'look, listen and learn' methods of field work which were more specific in their philosophical and moral positioning, and onto more participatory action research approaches.

The realities of fieldwork now are such that access to and acceptance by the community is critical for establishing a relationship and the development of that relationship is, "subtly intertwined with both the outcome of the project and the nature of the data" (Punch, 1986, p.12). Thus, community members and community-based researchers indicated that it is important to conduct research in the most open and transparent manner whereby research objectives,

methodologies and tangible benefits are negotiated with the community. Researchers interviewed indicated that considerable time and money is needed to establish such a relationship with a community and this may include preliminary visits, in addition to making contact by writing. Funding agencies need to account for these special requirements in their budget and should be prepared to allocate the extra expenses needed to be ethical in an Aboriginal context.

In spite of being open and transparent, a few community members interviewed highlighted that it is still the right of the community to limit access to the places and to information as it deems appropriate, to prohibit the research if they are uncomfortable with it either at the proposal stage or subsequently, and ultimately, to discontinue the relationship if the situation necessitates it.

To prevent these scenarios, the KORI consultation guidelines recommends that a contractual relationship be forged at least to the level of a contract setting out each side's expectations and the consequences that would follow if these expectations were not met. In the case of this study, a summary outlining the purpose of the visit and the details of each aspect of the research were submitted to the community contact (CC). Subsequently, feedback about modifications, additional considerations, and a general approval/disapproval of the project were received from the CC. The details of the research were then re-negotiated and the necessary changes on the summary were made. Following, approval for the project was finalized and a completed research summary was re-submitted to the CC for future reference and proof of our agreement.

Positive Outcomes

In terms positive outcomes from research, all of the community-based researchers and community members interviewed indicated that the majority of research conducted in the community has not been of benefit to the participants, but rather it has been of use to the information-gatherers. In response, they emphasized that researchers should not only plan to include community development initiatives in their research design but that they should also take on a more fundamental commitment to ensure that these positive outcomes materialize.

Once again, some of the community members and the community-based researchers interviewed spoke of transparency and stated clearly that it is desirable that the matter of project outcomes be discussed openly prior to conducting fieldwork. They also felt that the distribution of the benefits to the participants should be raised with, and considered by research ethics board (REB) and by the community leadership overseeing the project. The nature of these benefits should be relevant to the research project, appropriate in scale and apportioned appropriately (decided upon researchers and participants collaboratively). As outlined in the KORI consultation guidelines, compensation should also be provided to community co-workers, assistants and participants of the research where time is required to be spent outside normal and personal activities. In the case of this study, a meal consisting of food items such as fruit and deli meats which where not readily available in the community as well as small gift of a t-shirt was distributed as appreciation for all participants in the project. Monetary compensation was also provided to the individual who served as the CBRs.

In addition to any material benefits, researchers should include access to benefits such as employment, education and training. These outcomes enhance the effectiveness of fair and equitable interaction between the participants and the researcher. They also ensure that the

research becomes an invaluable learning opportunity for everyone involved and that the sharing of knowledge is a common benefit. In the case of this study, I field-tested KORI's consultation guidelines and recommended the necessary changes (Chapter Six) which will have an impact on the way research is conducted with the community in the future.

As highlighted in the literature, ultimately, every project should leave a legacy in the community that will have positive effects long after the project is completed. However, in practical terms, this requires a great deal of investment in time and resources on the part of the researcher and the funding organizations, respectively. Nonetheless, as highlighted in the conceptual framework, the investment in empowerment, capacity, self-advocacy and equitable relationships at the onset will incrementally benefit all those involved in the long term. As discussed in section two of this chapter, an institution such as KORI serving as an intermediary, combined with their consultation guidelines can ensure that these investments are made and maintained throughout the research process. The combination of roles and guidelines is quite new in Canada.   This way, communities will be empowered and capable of influencing the scope and direction of the research. As a result, they will benefit from increased recognition, respect, and potential resources as well as the quality of results and decisions will be significantly greater.

Research Methods

Both community-based researchers interviewed indicated that in building trust, research methods that are negotiated, readily understandable and transparent and are likely to gain support. In the case of this study, my own research methods were adjusted as I negotiated with KORI.   In accordance with local practices, the format of the meeting was negotiated to be a sharing circle

(similar to a focus group). For those community members who could not leave their homes, the CBR would contact them by telephone and if willing, arrange a one-on-one meeting so they could express their views on the topic of interest as well. It was also negotiated that no audio or video recording would be used to preserve sanctity and anonymity in the discussions.   Rather, notes would be made by the researcher on a flip chart and verified for accuracy by community members at the end of the interview.

Most researchers interviewed revealed that the research methods used in their studies were not negotiated with the community but rather their choices were based on their personal philosophical and moral positioning.   For example, some researchers in the social science discipline interviewed indicated that they needed to be immersed in the community to obtain an insider's view. Learning about the culture of the participants, their history, language, customs, expectations and aspirations is obviously necessary for the research process; however, if researchers become too immersed into the culture, then they could be under the false impression that they are able to think and act within the perspective of both their own culture and the one that they are studying and thereby become oblivious to what is unique. Furthermore, although communities expressed a desire for researchers to spend time in the community, some of the members interviewed indicated that they are not keen on having a full-time researcher live with them for long periods of time, which is required if an insider's view is to be obtained even in a limited way (Wax, 1971).

Another method frequently used by researchers interviewed is the administration and analysis of questionnaires. The questionnaire is methodologically flawed for cross-cultural research as it extractive and it assumes that the researcher knows enough in advance to identify the pertinent parts of a system and to prepare questions (Beebe, 1995). Many questionnaires are

based on validating models which are anticipated prior to fieldwork. However, it is difficult to identify site-specific systemic relationships particularly without contact with or visits to the community. Thus, questionnaires are an effective tool only when the researcher comes from the same world of meaning as the participants (Beebe, 1995). Tests for both validity and reliability are only accurate when the researchers communicate in the same cultural language as the participants, linguistically and symbolically. If this is not the case, participants may provide information based on categories of reality differing from those assumed by the questions (Beebe, 1995).

Some community members and community-based researchers interviewed indicated that there is a need for more participatory action research. Hoare *et al.*, (1993) define participatory action research as an approach that is driven by community member participation to examine social reality and the creation of local skill capacity for the purpose of creating community autonomy through praxis. Participatory action research is a collaborative process that is mostly advocated for working with marginalized and minority populations such as women, immigrants, and in Canada, the First Nation peoples (Hoare *et al.*, 1993) and there is also a long tradition of PAR in developing country contexts that merits to be adopted in the North.

Community members and community-based researchers interviewed highlighted that the Aboriginal culture is founded on different principles and ideals than the mainstream Canadian culture. Thus the key to the success of any shared process is the establishment of criteria, guidelines and agreements that reflect interest of all concerned. This ensures that the use of information obtained from the communities not only contributes to the objectives of the research but provides clear and tangible benefits for its holders in a culturally appropriate context. Participatory action research meets these criteria as consensus on research design is negotiated

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between parties <mark>well in advance of access</mark>. Maclure (1990) explains, "While participatory techniques vary, the over-riding purpose is to broaden the scope of participants' knowledge and skills and thus enable them to collectively initiate action or adapt innovation to their specific situations" (p.7). Thus, participatory action research is regarded as a practice of mutual knowledge and production. This method can also be expanded for use in interactive policy making whereby PAR is applied to test drive policies and make necessary adjustments accordingly (Mendelsohn & McLean, 2000; Ferreira *et al.*,, 2004).

For example, PAR principles were used to test the effectiveness of the KORI consultation guidelines. According to Pretty (1995), participatory action research methods tend to share the following characteristics:

- A defined methodology and systemic learning process that focus on the cumulative learning of all participants;

- Multiple perspectives; group learning processes that recognize that the complexity of the world will only be revealed through group analysis and interaction;

- Is flexible enough to be adapted to fit to each new context;

- Facilitators help people carry out their own study and analysis; and

- The process leads to critical reflection and action towards change, including local institution and capacity building.

Research methods (not exclusively PAR) preferred by community members and community-based researchers interviewed include <mark>open-ended and semi-structure interviews; case studies and oral histories, sharing circles and community meetings; visits to sites of significance; mapping and modeling activities; linkage maps; and Venn diagrams.</mark>

A frequently cited example of a successful participatory research approach by the community members and the community-based researchers interviewed was the

Telecommunications Workshop in Fort Severn facilitated by Dr. Ramirez and Dr. Richardson from November 30 to December 1, 1999. During this workshop, community members were given an opportunity to share their ideas regarding communication technologies in small groups using spray diagrams as a brainstorming exercise. This eventually led to the creation of rich pictures, which linked key stakeholders, ideas and concerns to be considered in strategic planning. Participants of the workshop enjoyed this experience as it brought various sectors of the community together, it was culturally appropriate and it provided each person with an equal opportunity to share their visions and concerns. (http://smart.knet.ca/archive/fsworkshop/index.html). Thus, the consensus among the community members and the community-based researchers interviewed is that frequent short-term visits to the field and the use of participatory research methods by researchers is more appropriate for the First Nations research context than effective long-term residence or the delivery of questionnaires.

Participation

Community participation can be defined as:

> An active process by which beneficiary or client groups influence the direction and execution of a development project with a view of enhancing their well-being in terms of income, personal growth, self-reliance or other values they cherish (Paul, 1987, p. 537).

The degree of community participation can vary from tokenism and manipulation of participants, to high levels of participation, where communities have real power and ownership of the change process. Arnstein (1969) discussed various types and levels of participation of communities in development projects. She proposed a typology of eight levels of participation and non-participation in an effort to clarify the confusion surrounding the use of this term

(Appendix 5). Each rung in Arnstein's ladder represents a different extent of a citizen's power in determining the end product. On rungs 1 and 2 of the ladder (bottom), participation is somewhat superficial in that the real objective of allowing the involvement of a citizen is to 'educate' or 'cure' the so-called participants. Rungs 3 and 4 of the ladder allow the participants to have some voice in the project but only in a token way. At this level the participants are not give the control to ensure that the tradition power-holders will heed their views. Rung 5 is simply a higher level of tokenism because the participants may advise but they cannot decide. On rung 6, citizens enter a partnership that enables them to negotiate and engage in trade-offs with traditional power-holders. On rungs 7 and 8 (top), citizens gain the majority of the decision-making or managerial power. In presenting such a ladder, there is a danger in assuming simplistically that in all contexts, the higher up the ladder of participation, the better. However, for the purpose of this study, Arnstein's model will be used to discuss the following responses on research participation in Fort Severn.

All of the stakeholders interviewed spoke of challenges associated with participation in community research. Community members and community-based researchers felt that outside researchers were not providing meaningful engagement for the community (Rungs 1 to 4 of Arnstein's Ladder) whereas outside researchers felt that it was difficult to recruit participation from the community. In the case where individuals decided to participate, researchers interviewed indicated that many were reluctant to share personal information.

In most cases, the willingness of First Nations people to participate in research studies are dependent on factors such as level of interest, availability, time, family commitments, political alignments, perceived need for the study and perceived benefits on both the individual and the community. Thus, the opportunity to participate does not necessarily result in participation.

Most of the community members and the community-based researchers interviewed indicated that that they would be less likely to decline to participate if the research has been introduced to them first through a series of events. This may entail announcements on the community television or radio channel, flyers posted around frequented areas of the community, followed by a community meeting to introduce the research team and the projects. The community needs several opportunities to the meet the research team to ask questions and discuss whether to participate and on what terms. In the case of this study, information was relayed through posters (Appendix 3), which were displayed throughout the community in areas such as the health centre, the youth centre and the grocery store as well as relayed the message through telephone. Special permission was also obtained from the CC to advertise the gathering on the community channel and the local radio station. Contact information for the CBR as well as KORI was included to address any inquiries from the community.

A few of the community members and the community-based researchers interviewed also indicated that another way for researchers to overcome the barriers to participation is by developing partnerships within the community, especially with leaders. Leaders in the community can help legitimize the research project and encourage local participation. However, even upon availability, two of the researchers interviewed stated that one of the most difficult tasks is recruiting participation from community leaders as a collective.

The challenges of bringing leaders together, as identified by researchers interviewed, may be attributed to numerous factors, the first of which concerns accountability. As Aboriginal leaders, they are responsible for addressing mainstream government financial requirements as well as for meeting cultural, kinship and family obligations in the community. Thus, community members interviewed indicated that leaders often find themselves caught in an endeavor to

reconcile these two systems of accountability. This two-fold responsibility also means that the leadership is liable for addressing difficult questions raised by research. For example, why previously government funded programs, such as providing translators for health care patients, have been suddenly discontinued when there is a demand for it in the community? Is it because the community failed to file a report with the government on time? Was the report not filed because it required that the community provide information that they were not willing to share? Is the community's confidentiality more important than continuing essential programs? If leaders do decide to participate in a research study, it is likely that they will be asked such challenging questions.

One of the community-based researchers interviewed highlighted that another problem with participation in research is that discussing such issues out in the open may cause internal conflicts as the leadership as a collective may not have a consistent view. The dynamics of kinship and social gatherings, events, behaviors, organizations and processes in a community may also influence the leader's decision to participate in a group setting. As discussed by community members and community-based researchers interviewed, family obligations shaped by Aboriginal customary law, may prohibit the disclosure of a particular issues to researchers or perhaps, the political and financial interests of a family may be at odds with a collective discussion.

The potential to gain commitment from the local people, governments and organizations to bring about change may be increased through the use of participatory research (Rungs 7-8 of Arnstein's Ladder). However, even with participatory methods, researchers must consider the dynamics of community power structures. At least two of the researchers interviewed were unaware of local issues concerning power and knowledge, as rules and rituals associated with

various aspects of knowledge are highly variable, closely resemble social structure, and are frequently reinterpreted by the community (Maclure, 1990). Thus, power structures may favor a higher level of participation from certain individuals in the community while assigning more passive roles to others, even though all are ostensibly involved in the research (Maclure, 1990). Thus, both community-based researchers interviewed stated that the onus is on the researcher to provide multiple avenues so that there is maximum awareness, access and equal participation (Rungs 7 and 8 of Arnstein's Ladder) by everyone in the community who wishes to contribute to the project.

Ownership, Control, Access, and Possession (OCAP)

Of particular interest for discussion in this chapter with respect to research ethics are the principles of ownership, control, access, and possession (OCAP) advocated for by the National Aboriginal Health Organization (Schnarch, 2004) . The right of communities to own, control, access and possess information about their peoples is fundamentally linked to self-determination safeguarding their culture. The principles assert:

Ownership: refers to the relationship of First Nations to their cultural knowledge/ data/ information. The principle states that a community or group owns information collectively in the same way that an individual owns his/her personal information.

Control: The principle of 'control' affirms that First Nations, their communities and representative bodies are within their rights in seeking to control over all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project-from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information and so on.

Access: First Nations must have access to information/data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to

their collective information. This may be achieved, in practice, through standardized, formal protocols. (Schnarch, 2004)

Possession: While 'ownership' identifies the relationship between a people and their information in principle, possession or stewardship is more concrete. It refers to the physical control of data. Possession is a mechanism by which ownership can be asserted and protected.

Government agencies have been less than satisfied with the limitations of access suggested by OCAP formula. They assert that maximum social benefit of publicly-funded research necessitates open access to data with the customary provisions for protecting the privacy of individual participants. However, the findings in this thesis indicate that there needs to be a more appropriate and enforceable protection of First Nation interests in research activities and this can be done through recognizing OCAP. There are visible benefits for incorporating OCAP particularly in terms of response, efficiency and quality of results.

These differences in positions between the First Nation and government parties have not yet been resolved but communities are increasingly rejecting blueprint proposals created by researchers and funding agencies and insisting on community control. This means one of two things: communities will have to assume full responsibility for conducting research or more realistically (as suggested by this chapter) collaborative research relationships where the respective responsibilities of community and outside researchers are set out in a contract will need to be established. However, the First Nation is wary that the principles OCAP will be dismissed as the administration of existing guidelines are in the hands of REBs located in universities and institutions from which First Nation communities are generally distant socially and culturally.

Summary

In the previous sections in this chapter, I discussed stakeholder responses with respect to power and consent, ownership, building relationships, and positive outcomes. Emphasis was also placed on the preparation required for fieldwork in terms of contacting community representatives, employing intermediaries and determining appropriate research methods and tools. Important among those matters relating to the development of a research project was the view that every project must be negotiated so as to involve individuals or the whole community, from the formulation of the terms of reference, to the discussion of how to find solutions, to the interpretation of findings. Meeting the needs of Aboriginal research, as demonstrated by these findings, is the rationale for using a participatory action approach as an effective and efficient methodology for implementing research in this context. Nonetheless, one of the challenges for the researchers involved is the costs of negotiating research agreements. Prior to a grant being awarded there are few if any funds to consult with communities and to ensure that the research project meets the needs and reflects the community's concerns. While it is possible to work out such details in advance there is also the possibility that funding may not be forthcoming. Another key difficulty for researchers lies with the multiple levels of approvals to achieve respectful research relationships. As described in Chapter Three, three different levels of approval were required to clear the way for this research study to proceed; at the university level (University of Guelph Research Ethics Board), intermediary organization level (KORI) and the community level (Fort Severn community). Refusal and redefinition was possible at every level. This is further complicated by a changing and evolving political context within which it is often necessary to renegotiate approval while the project is ongoing. As described in the literature

review in Chapter Two, all of this is exacerbated by the long history of colonialism that is a constant backdrop to any engagement in an Aboriginal community.

As stakeholder responses in Chapter Four demonstrate, establishing a collaborative research process is not simple, yet there are real academic and socio-political benefits in doing so. Academically, the research results have the potential to be stronger, more detailed and ultimately more accurate than research conducted in the context of distrust, deception and inequality. For the First Nation, negotiating research also provides an opportunity to discuss and incorporate aspects of OCAP. Admittedly though, a collaborative research process will very likely be slower, more drawn out and require more funding that if it was a non-collaborative project.

Chapter Six: Conclusions and Recommendations

This chapter presents conclusions and recommendations for First Nations communities, non-First Nations researchers, funding agencies, intermediary organizations and research ethics boards on designing and implementing a research project. The conclusions and recommendations are presented in eight headings which were derived from the discussion in Chapter Five: Entry; Negotiating research; Benefits of Research; Consent; Confidentiality; Ownership and publication of data; Investment of time and funding; and Intermediary organizations. I then present a summary of all the recommendations. Finally, I present the concluding remarks with implications for conducting collaborative research and point to future directions of study.

Entry

In the First Nations, entry into the community "is the stage in which the basis for the research relationship is formed" (Serrano-Garcia, 1990, p.176). Entry into the community, as identified by Johnson (1984) and Hutchinson (1985), consist of four steps: stopping, waiting, transition and entry. Awareness of these stages and how to facilitate the process is essential for a researcher's entry into the community.

The first step, stopping, occurs when a researcher is impeded from entering the community through formal or informal means. This stage is critical as moving into consecutive stages will be contingent upon how the activities and intentions of the researcher are perceived by the community. If the researcher decides to move forward despite community disapproval, the results may be unreliable as community members may not share their genuine reflections. The second step, waiting, is similar to the stopping phase as community members evaluate whether the researcher is trustworthy and the research merits investment of community time and resources. The third step, transition, is when the community researcher is allowed to become

involved in some community activities. Entry, the final step, only occurs when trust is established and feelings, concerns and visions are shared openly with the researcher.

Developing entry into a First Nation community involves preparation on the part of researcher before seeking cooperation from communities. This involves cultural encounters which familiarize the researcher with the community. This includes spending time in the community, learning about the culture and history as well their visions for the future. Learning about the community will assist the researcher in determining whether her or his goals and the community needs are compatible. It will also provide the researcher with the opportunity to gain an in-depth understanding of community dynamics, infrastructure and internal procedures; this foundation is important as research designs that do not take into account the social and political realities of the population can result in a misinterpretation of data. It is also important to consider that the acceptance of a researcher by a community will be affected by previous personal experience with research partnerships and may either hinder or facilitate the entry process. Thus, REB's must accommodate for these entry steps when researchers are seeking approval to work with Aboriginal communities.

Researchers need to understand that cultural awareness, knowledge, and skills are a necessity when establishing a relationship with a First Nation. Researchers need to observe cultural protocols when approaching a community to explore their interests. The first of these protocols involves the researcher contacting the Chief and Council to request permission to establish a relationship with the community. The Chief and Council are administrative governance structures that were established during the time of colonization when there were numerous attempts to undermine traditional authority. Traditional authority structures such as the Chief and Council are often overlooked by researchers as a starting point for research but

they retain considerable influence over the community. It is argued that working with the Chief and Council can compromise community representation, however, as I found during this study, there may be little choice and the trade-off may be greater in terms of in-depth and on-site understanding by the outside researcher. In addition, any information disseminated in the community will have to be done at the discretion of the Chief and Council.

Currently, the KORI consultation guidelines only mandate that the Chief and Council be contacted for initiating research. However, once permission has been obtained to commence a relationship with the community, KORI must encourage researchers to foster a relationship and facilitate entry by doing one or more of the following: touring the community, volunteering at local organizations, participating in community events and excursions, attending workshops and conferences, as well as reviewing publications and reports available about the community. It is essential for researchers to take the time to familiarize themselves with the research setting and to develop a relationship with the community. This helps to facilitate entry on the basis of mutual trust and respect; especially in First Nations, where communities have been abused by academic institutions, the government and other research organizations. Researchers need to understand that relationships of trust and respect are the foundation for ethical research practice. This requires a great investment in time, self-disclosure, valuing differences as well as genuine caring and concern for the community as well as devolution of power before discussions about research can proceed.

Negotiating Research

Once a relationship has been established with the community, research interests must be negotiated. The process of negotiating research with First Nations takes time and patience from both the community and the researchers. Negotiating research should also involve agreements on a set of working principles that articulate both community and academic expectations, to guide interactions between participants and researchers throughout the project.

When conducting research in First Nations communities, the use of a participatory action research (PAR) approach is strongly recommended as it contributes to a balancing of the historical record in a First Nations voice, it increases the chance of development effectiveness and longevity, and the methods are consistent with First Nations values of decision-making as a collective. In PAR, the research agenda is negotiated in collaboration with, and guided by the needs of community. The researcher submits an idea for research which is then further discussed and negotiated with community partners. The researcher and the community jointly set the research agenda, including the agreement on the topic to be studied and in what manner it will be studied, thus assuring that the research project is culturally sensitive and responsive to community needs. Building capacity for the community as part of the research methodology, including data collection, analysis and dissemination are also negotiated in participatory process.

It is important for researchers to consider that the use of PAR may present challenges in the institutional setting. For example, the KORI consultation guidelines state that to be ethical in an Aboriginal context, elements of consent, recruitment and ownership need to be negotiated with the community as part of the research design. This requires contact with the community prior to formal approval granted by REB, which is generally discouraged. Thus, there is a need for REB's to acknowledge First Nations perspective in all aspects of research ethics processes;

from the development of guidelines, to implementation and monitoring, as well as protecting the interests of the people in a way that is appropriate for the cultural context. REB's without the help of required expertise may reduce ethics to a focus on procedures rather than on the substance of research. Thus, REB's could benefit from consulting community representatives, First Nations researchers or other experts familiar with research ethics issues relevant to the proposed research. Researchers wishing to conduct research in the First Nations must also take responsibility for speaking with REB's to ensure a compromise between institutional and First Nations ethics is achieved. A compromise is possible as demonstrated by this research where the REB at the University of Guelph permitted that a relationship could be established with the Fort Severn community according to the KORI consultation guidelines. There is also a need for community representatives to engage the Tri-Council in the development of an ethics protocol particularly designed for First Nations-based research.

Following discussions with REB's, the next step for researchers is to discuss their interests with the appropriate community representatives. With respect to the KORI consultation guidelines, this has involved submitting a summary to the Chief and Council articulating the goals, objectives, roles, expectations and projected outcomes of the partnership and ensuring that there is a common vision. However, in the past, the KORI consultation guidelines have not required researchers to provide details about information obtained in terms consent, confidentiality, ownership, publication and dissemination. To address this issue, it is recommended that KORI, in collaboration with communities, develop a standardized research proposal form with an attached contract to formally negotiate their working arrangements with the researchers. This form should ask the researcher to describe the research question, methods of collecting data, consent and confidentiality, benefits and risks, capacity building and

empowerment components, data ownership and dissemination, funding, and the use of intermediaries to ensure that the community truly understands the nature of the research. The community and KORI can then provide feedback with respect to the feasibility, methodology, appropriateness of the project for the community. It is important for researchers to take note of this feedback and listen to the strategies and methods that have worked in their community to foster strong research partnerships in the past. For instance, community representatives can inform researchers about the best way to reach out to community members. This feedback process also involves the researcher sharing with the community their knowledge, which will help protect the research methodology. Being transparent and open-minded about community ideas opens the door for the community to listen to the researcher. Furthermore, developing a continuous process for stakeholders to be a part of the decision-making process and providing on-going feedback and input facilitates a truly collaborative relationship.

Benefits of Research

It is essential for researchers to address the issue of equity with the community with respect to the conduct and implementation of the research project. It is recommended that researchers account for community-based expenses in their budgets as the community has the right to be compensated for any expenses accrued during the research process such as research assistants, translators, travel and use of facilities. KORI has made financial compensation to communities a requirement in their Community Consultation Guidelines, however this will require awareness and cooperation from funding agencies as costs for researchers will increase significantly.

In addition to financial compensation, KORI, in their consultation guidelines, must make it essential for researchers to transfer skills to the community so that the people have the capacity

as well as access to decision making processes, to make informed decisions about the issues which affect them. The transfer of skills can begin with sharing research funding with the community through a subcontract to a community-based organization, recruiting and training local staff and consultants, facilitating workshops and an ongoing process of building community control and shared leadership at all levels of the research. However, this will require cooperation from the community as well as KORI in terms of recruiting individuals to be trained, conducting a needs assessment, developing learning objectives and then designing a plan accordingly. It will be difficult for researchers to incorporate such measures into a project in terms of time and funding without an internally developed plan designed by researchers who have had previous experience with capacity building.

Capacity building needs to be an integral component of the research process as it ensures that individuals and their families have the means and opportunity to participate fully in their local community and the wider society as they choose. However, REB's and funding organizations do not have a history of necessitating community capacity building initiatives as part of the research process. Capacity building, in whatever form, should respond to community needs through a multitude of initiatives, programs and services, which are ultimately aimed to enhance the sustained ability of the local people to make informed decisions about issues of importance to them. However, in order to do facilitate this, there needs to be clarity and agreement between communities and researchers about what community capacity actually means in terms of its application and impact on communities. What is needed by researchers is a move from rhetoric to reality in terms of the development and implementation and more recognition and respect for the existence, and potential involvement, of the collective strengths, skills,

knowledge and wisdom and network relationships which First Nations people possess, and which should be sought and utilized in any research initiatives.

Consent

Consent is informed when:

> It is given by a person who understand the purpose and nature of the study, what participation in the study requires a person to do and to risk, and what benefits are intended to result from the study (Council for International Organizations in Medicine, 1995, p.247).

Most definitions of consent apply to individuals, and as of yet, no commonly applied principles exist for the consent of communities as a collective. Collective risks, such as culturally specific risks, are a major concern for many First Nations communities and as such, communal consent becomes necessary along with individual consent. The REB's at academic institutions require statements of potential harm or risks to participants, but these are also usually framed in terms of individual participants, not collective or community-based risks. A problem arises when researchers interview individual members of a community in their own right as individuals without regard to the interests of the community as a whole and without seeking permission from traditional authority when the approval of the collective community is required. REB's may not be in a position to recognize and protect all potential harms from research. Thus, REB's need to recognize that developing procedures for consent in a participatory fashion, can minimize potential harms such as external stigmatization, self-stigmatizations and community disruption, which the community would be more sensitive to.

It terms of addressing the issue of consent with communities, the KORI consultation guidelines suggest that oral consent be used instead of written consent on the condition that a witness was present in all situations and that the consent form is read to potential participants in

an acceptable manner and language, and at a level and speed that permit comprehension. Clarification is provided as needed and the participants are informed that they can continue or end the consultation at any time and that they may agree or refuse to participate without penalty. However, it is recommended that in addition to developing an oral consent procedure, KORI require that researchers provide a description of the research and explain the information at both the community and individual level so that both individual and collective consent are addressed. This will lead to less resistance and higher level of cooperation and collaboration from the community. In fact, KORI should require prospective researchers to outline in a proposal exactly what the risks and benefits of the research will be at an individual and community level. A separate statement should be made with respect to the risks, including potential environmental, legal, financial, social, physical, or psychological risks and how these will be explained to the community and the study participants. There also needs to be a discussion about the need to provide community training on the benefits and problems with various methodologies so that communities can make informed decisions about which methodologies are appropriate for them.

When the development of a research agenda is initiated by the community and/or designed to assist the researcher in a specific need, this facilitates shared accountability and ownership of the research process and results as well the sustainability of the project over time. However, when the project is initiated by outside researchers and organizations (as is usually the case), early involvement of the community in setting research priorities and negotiating research design is critical for partnership success. As Piquemal (2001) stresses, consent is not a one-time formality but an iterative process. Consent must be constantly negotiated and renegotiated with communities; particularly in the initial development of the research proposal and if and when changes are made to the research design at any stage. Thus, it is recommended that researchers

facilitate one or more community meetings to explain the research goals and the potential risks and benefits to the community. Researchers should also inform the community at every stage that participation in the study is based on individual volunteers and that collective consent in support of a research project constitutes the willingness to promote the research not a commitment of individual participation. As well, communities should reserve the right in the guidelines to suspend research activity if the project becomes unacceptable. In addition, it is recommended that feedback session continue during the research process for ongoing project evaluation and to ensure correct collection and interpretation of data. This may be best facilitated by monitoring committee at the grassroots level as proposed by many community members. Furthermore, it is recommended that upon completion of the study, First Nations professionals in the field of study be invited for peer review of the project.

Confidentiality and Anonymity

In addition to consent, confidentiality and anonymity must also be discussed in terms of protecting the community and the individual. Confidentiality and anonymity are critical in First Nations communities as specific communities do not want to be identified in publications. In the case of this study, the Chief and Council of Fort Severn indicated that community anonymity was unnecessary however the anonymity of individual participants was required as private information can easily become public knowledge in small, close-knit communities. The KORI consultation guidelines have not addressed the issue of confidentiality and anonymity aside from requiring a statement in the oral consent procedure ensuring that the interviewee will remain anonymous and that the information collected from interviews will remain confidential; however, there is no explanation to the participants as to how this will be done. Thus, it is

recommended that KORI require the prospective researcher to provide a statement in their research proposal about how confidentiality and anonymity will be protected and how participants will be informed of the degree of confidentiality that will be maintained through the duration of the project as is required by standard REB forms. They should be able to indicate any circumstances that may lead to a breach of confidentiality and negotiate the ramifications with the community. With respect to community access to information, conventional protocols require that at differing stages of research, the form and access of data is changed accordingly. When the data is raw in the form of notes, access should be reduced to the interviewers, the participants, the transcriber and the primary investigators. At the second stage, any identifying markers should be removed through a process of member checking in which the researcher reviews each interview with the respective participants to ensure correctness of the data and privacy of the participants. Once this is completed, the data can be made available to the larger research group. Finally, in the third stage when the data has been analyzed and thematically organized into findings, the access can expand to the First Nations community (including the Chief and Council) and to the larger research community. Ideally, the researcher should present the information from the study in-person; however, if he or she cannot re-visit the community, the information should be shared through videoconference (as will be the case with this study).

The KORI consultation guidelines should ensure that researchers and communities adhere to the above system as it will provide community members, particularly those who have provided information that is very personal and sensitive in nature, with a sense of confidence and security as well as an added assurance of confidentiality. This recommendation is in response to a number of incidences where privacy rights were inadvertently violated by certain leaders and

members of organizations in the community when information was made available without marker removal or member checking.

Procedures in terms of storage and management of data collected including the access and availability of information have also not been specified in KORI's consultation guidelines. A standard item that remains in many ethics protocols is a declared intention to destroy the data after a specified number of years following the end of the project funding period. Many community members interviewed stressed that by discarding data collected from research projects, there is a risk that valuable information, such as the elder's testimonials, might be lost and unheard by generations to follow. Thus, researchers and communities must negotiate the public use of research results. To the extent of the KORI consultation guidelines, an agreement was verbally negotiated with the community about the storage and management of the finalized results. The agreement entailed that a hard copy of the thesis would remain at the band council office and the KORI office but details about the raw data were not discussed. A verbal agreement is insufficient because it is not binding in a research context. Thus, KORI needs to incorporate a written contract in which the details of the community's and the researcher's concerns about the appropriate use of raw data and finalized research results could be specified and subject to arbitration if necessary. Ideally, the contract should be based on the consent of the participants in terms of whether their personal raw data will be stored with the researcher or the community and whether this data should be archived or destroyed.

Ownership and Publication of Data

Community control over data and publication of data may be the best means of protecting confidentiality in the First Nations, however most universities (as a result of the TCPS which has not taken a definitive stance on the issue and left it at the discretion of the REB) discourage or

prohibit researchers from giving up ownership of data to the communities. Ideally, issues of data ownership and publication should be negotiated prior to commencing a project and should include specific mechanisms for dealing with conflicting interpretations or inappropriate use of data collected. With respect to the KORI consultation guidelines, the publication of results was negotiated. It was agreed that once this thesis was completed, a clear, easy-to-read, accessible format of the findings and conclusions would be made available on-line at www.knet.ca for the community. Ownership of data on the other hand, was not discussed although it is clear where communities stand on that issue. Even though communities continue to advocate for the principles ownership, control, access and possession (OCAP), it is unlikely that REB's will agree to relinquish all control of data to the communities until specified by the TCPS. Nonetheless, it is recommended that REB's consider six key guidelines developed by Maddocks (1992) with respect to ownership and publication of data: (1) Researchers have an ethical obligation to report findings to community; (2) Raw data belongs to the community; (3) No publication should identify the community or individuals without permission (particularly photographs) ; (4) Acknowledgement of Aboriginal assistance; (5) Permission should be sought by researchers from community before comments are made about research to media to avoid derogatory or stigmatizing remarks; and (6) A processes for resolving disputes should be included.

One way for KORI to enforce these six guidelines is to necessitate regular meetings with various stakeholders to discuss the compilation of the data following the completion of the study. When it appears that one of the stakeholders disagrees with an interpretation of the data, he or she should be invited to discuss their concerns as an addition to the main data. Then as a group, the stakeholders can decide whether this new information or interpretation should be adopted as part of the final results. It is important to consider that while facilitating such a process, it is

difficult to prevent politics from skewing interpretations of the data. The interpretations of each individual are shaped by the context of their intentions and assumptions. However, stakeholder meetings provide a safe forum for discussion and negotiation of intentions and assumptions so that extreme solutions and unresolved disagreements can be avoided. Implementing this process will take time and cooperation from all stakeholders. Although official stakeholder meetings were not incorporated in this study, an effective and efficient way to facilitate this process in the future would be to pre-assign one representative from each stakeholder group to participate in regularly scheduled meetings with KORI through on-line discussions or videoconference until the project is completed.

In terms of publication, the cases where it is sought, it is recommended that the researchers collaborate with community representatives to write the manuscript. Co-authoring can be valuable as it provides the opportunity for a myriad of perspectives which can enrich the research outcomes. When manuscripts are not co-authored, representatives should reserve the right to review the drafts prior to publication in order to ensure that the integrity of the community and its constituents are protected. In the case where the community representatives completely opposes the publication of research results, the researcher should not publish the results except for providing summaries to academic and funding agencies where continued sponsorship necessitates progress reports. Since the community is heterogeneous, there is no guarantee that the representatives will speak for the interests of the whole community. Nonetheless, this process offers to, at the very least, protect the community from potential exploitation and it emphasize provisions of accountability for all stakeholders.

Investment of Time and Funding

History shapes all relationships in one way or another. Research with First Nation communities is constrained and defined by a history of colonization, oppression, and lack of enfranchisement. Academia has had a less than honorable part in this history, often, treating First Nations communities as field laboratories (Piquemal, 2001). Therefore, it is essential that the TCPS develop policies in collaboration with the First Nation to guide research. Without taking a definitive stance on collective consent and ownership, REB's and researchers are given the go-ahead to conduct research in manner that is unethical and culturally inappropriate. Furthermore, additional time is also required for researchers to develop relationships of acceptance and trust with communities. Time is also required for long-term and continuous re-negotiation of the terms of consent, ownership and publication of data. However, research councils and funding agencies usually operate within a short time frames with a review of the research framework on a one-time basis with yearly updates. This is of concern because researchers can provide valuable research services to communities, but with pressure to write and publish research findings they tend to focus on predictable results that rarely advance the state of knowledge, services or programs in the community. Thus, research councils and funding agencies need to be structured for more flexible (e.g. allow for entry steps) and long term arrangements (e.g. allow for cultural encounters and consultation) in a context of capacity building. A long-term funding commitment is necessary because short term trial projects risk simply using people, their time and their data, and jeopardize further partnerships in the future. Accepting the *status quo* of short term engagement without a corresponding commitment to work for and implement solutions can in fact have a more negative than positive long-term benefits.

Intermediary Organizations

By its nature, participatory research requires the input of a number of stakeholders. Coordinating these inputs is a major task in itself. Thus, there is a need to establish a formal network to facilitate the brokering process between researchers and First Nations communities. The employment of a dedicated intermediary organization such as KORI, with representation on the ground, can fulfill such a need.

Facilitating participatory action requires specialized skills and knowledge as well as extensive experience and training, which are often overlooked and undervalued. Too frequently, new researchers delve into the field without any preparation and find it difficult to adjust to community based processes or to certain positions such as facilitators of change. Intermediary organizations are recommended for these types of researchers as these organizations hire community-based researchers (using the researchers' budget) to assist with local knowledge collection and to ensure that researchers are aware of and sensitive to community's culture and needs as well to the political and social structural contingencies that will facilitate or impede the research. They provide guidance to researchers on how to make research interventions relevant and acceptable to communities. They may also give the researcher and the project credibility at the initial stages with the community members and those of other communities.

For communities, the assistance of an intermediary organization is also recommended as community-based researchers can function as an advocate in systems (education, health and government) where their voice is lost as a result of powerlessness. This approach is also consistent with empowerment and self-advocacy. The community-based researcher as a representative voice in the research process can ensure that partnerships are based on mutual respect, critical reflection and group participation whereby communities can gain access to and

control over their resources and affairs thereby contributing to the empowerment and self-advocacy agenda.

Although it is critical to have an intermediary organization to mediate stakeholders from differing knowledge systems and their roles as facilitators of exchange of this knowledge, the cost of doing so is extremely expensive. Hiring an intermediary organization, which then employs a staff member to accompany the researcher in addition to employing a community-based researcher, can increase the budget by two-fold. Thus, funding agencies either need to account for this expense when providing research grants or intermediary organizations need to find a way to make this process more affordable. One way for KORI to reduce the cost for researchers is by decreasing the number of intermediaries involved in the process. Rather than having a staff member accompany the researcher, the researcher should establish a relationship with the community contact and community-based researcher either during an initial visit to the community or over videoconference. This way, the researcher is familiar with faces and places in the community upon arrival thus eliminating the need for, and costs associated with, an on-site KORI employee. In addition, KORI must create standardized research proposal forms and contracts for conducting research in KO communities (as discussed in the section titled Negotiating Research), so that expenditures for administration in terms of both time and money, can be further reduced.

Table 6.1 provides a comparison of three different research approaches: the conventional Research Ethics Board (REB)-Based Approach, the KORI Community Consultation Guidelines Approach, and the Thesis-Recommended Approach. The Thesis-Recommended Approach accounts for stakeholder responses reported in Chapter Four, as well as strategies for research and competencies for practice as highlighted in the literature in Chapter Two.

Following Table 6.1 there is a summary of more detailed recommendations for KORI, researchers, research councils and funding agencies as discussed above in Chapter Six.

Table 6.1: Comparison of Research Approaches: REB, KORI and Thesis-Recommended

Conventional REB-Based Research (Appendix 6)	KORI Consultation Guidelines (Appendix 1)	Thesis-Recommended Approach (*terms from literature)
In order to comply with the Tri-Council Policy Statement, a researcher who proposes to use human participants must apply for clearance from the University. Commencing research without prior approval of the REB is unacceptable and will result in penalties.	The KORI Community Consultation Guidelines are to be used to prepare researchers who wish to visit a KO affiliated community. It is a compilation of experiences and suggestions offered by staff from a number of KO departments, community-based researcher and community members.	**A.** **Researchers approach the REB to ensure a compromise between institutional and First Nations Ethics can be achieved**
The researcher is required to fill out the following sections in the REB application form and submit for approval:	The following steps are recommended for preparation for a community visit:	-> *(advocating for community partnership*)*
Section A – General Information	**A.** **Permission from Chief**	**B.** **Researchers approach KORI and express their interest for research & employ KORI to broker the research process**
1. Title of Research Project	**B.** **Fax Research Summary Sheet to Band Office**	-> *(consistent with community empowerment* & self-advocacy agenda*)*
2. Investigator Information		
3. Proposed Dates of Commencement	**C.** **Call Community (CC)**	**C.** **KORI enforces the four steps for entry:**
4. Location	**D.** **Fax Research Summary Sheet to CC**	1. *Stopping* - Contact Chief and Council and Submit Standard Research Proposal form to Band Office
5. Other Research Ethics Board Approval	**E.** **Call Community-Based Researcher (CBR)**	2. *Waiting* - Obtain Approval from Chief and Council
6. Level of Project	**F.** **Negotiate Contract**	3. *Transition* - Call Community Contact (CC), Submit Proposal to CC, Call Community-Based Researcher (CBR)
7. Funding of the Project	**G.** **Get Updates**	4. *Entry* - Visit the Community and Participate in Activities, Establish a rapport with community
8. Conflict of Interest		
9. Rationale	**H.** **Community Visit**	-> *(cultural responsiveness*, engaging in cultural encounters* & obtaining cultural knowledge*)*
Section B – Summary of Proposed Research	1. Meet with Chief and Council	
10. Methodology	2. Meet with Elders	**D.** **Researchers negotiate with Community. Discuss:**
11. Experience	3. Meet with Youth	1. Research question
12. Participants	4. Facilitate Community Meeting	2. Methods of Collecting Data
13. Recruitment		3. Consent
14. Compensation	**I.** **Follow up**	4. Confidentiality and Anonymity
		5. Benefits and Risks
Section C – Description of the Risks & Benefits	**J.** **Submit Final Results for Editing**	6. Capacity Building and Transfer of Skills
15. Risks	**K.** **Submit Final Results**	7. Data Ownership and Storage
16. Benefits		8. Dissemination of Results
	L. **On-going Engagement**	9. Budget Distribution
Section D – Informed Consent		-> *(ensuring community participation* & capacity building*)*
17a. Informed Consent Procedures		
17b. Deception		**E.** **Finalize Negotiations in a Written Contract**
18. Consent by Authorized Party		-> *(solidifying community partnership*)*
19. Alternative to Prior Individual Consent		
20. Participant Feedback		**F.** **Researchers Submit Application to REB**
21. Participant Withdrawal		**G.** **Community Visit**
		1. Meet with Chief and Council
Section E – Confidentiality		2. Meet with Elders
22a. Confidentiality		3. Meet with Youth
22b. Privacy		4. Facilitate Community Meeting
22c. Procedures for Securing Confidentiality		-> *(during visit, demonstrate: caring*, cultural self-awareness*, cultural sensitivity*y, cultural skills* & valuing differences*)*
22d. Destruction/Long-term Storage of Data		
22e. Degree of Anonymity/Confidentiality		**H.** **Follow-up with Stakeholders Meetings**
		-> *(community participation*)*
Section F- Monitoring On-going Research		
23a. Annual Review		**I.** **Submit Final Results for Editing and Peer Review**
23b. Adverse Events		-> *(community participation*)*
Section G – Signatures		**J.** **Submit Final Results to Community and Institution & On-Going Engagement**
		-> *(community participation* & partnership*)*

Summary of Recommendations

Recommendations for KORI

❖ KORI must ensure meaningful involvement of the community in the research process from the very beginning by encouraging the establishment of a formal arrangement in the form of a reference group, mentor arrangement, or a monitoring committee at the grassroots level.

❖ KORI must encourage researchers to foster a relationship and facilitate entry by doing one or more of the following: touring the community, volunteering at local organizations, participating in community events and excursions, attending workshops and conferences, as well as reviewing publications and reports available about the community.

❖ KORI, in collaboration with communities, develop a standardized research proposal form with an attached contract to formally negotiate their working arrangements with the researchers. The form should include the following:

- Researchers should be asked to describe the research question, methods of collecting data, consent and confidentiality, benefits and risks, capacity building and empowerment components, data ownership and dissemination, funding, and the use of intermediaries to ensure that the community truly understands the nature of the research.

- Researchers should be asked to provide a description of the research and explain the information at both the community and individual level so that both individual and collective consent are addressed.

- Researchers should be asked to outline what the risks and benefits of the research will be at an individual and community level.

- A separate statement should be made by researchers with respect to the risks, including potential environmental, legal, financial, social, physical, or psychological risks and how these will be explained to the community and the study participants.

- Researchers should be asked to provide a statement in their research proposal about how confidentiality and anonymity will be protected and how participants will be informed of the degree to which that will be maintained through the duration of the project.

- Researchers should be able to indicate any circumstances that may lead to a breach of confidentiality and negotiate the ramifications with the community.

- Researchers should indicate how capacity building will be incorporated into the research. Capacity building should respond to community needs through a multitude of initiatives, programs and services, which are ultimately aimed to enhance the sustained ability of the local people to make informed decisions about issues of importance to them. However, in order to do facilitate this, there needs to be clarity and agreement between communities and researchers about what community capacity actually means in terms of its application and impact on communities.

- Researchers should indicate what skills will be transferred to the community so that the people have the capacity as well as access to decision making processes, to make informed decisions about the issues which affect them. The transfer of skills can begin with sharing research funding with the community through a subcontract to a community-based organization, recruiting and training local staff and consultants, facilitating workshops and an ongoing process of building community control and shared leadership at all levels of the research.

❖ KORI should inform the researcher that the community reserves the right to suspend research activity if the project becomes unacceptable.

❖ KORI should necessitate the researcher to facilitate feedback sessions. These sessions should continue during the research process for ongoing project evaluation and to ensure correct collection and interpretation of data.

❖ Upon completion of the study, KORI should invite First Nation professionals for peer review of the project.

❖ With respect to community access to information, KORI should enforce conventional protocols which involve that at differing stages of research, the form and access of data is changed accordingly. When the data is raw in the form of notes, access should be reduced to the interviewers, the participants, the transcriber and the primary investigators. At the second stage, any identifying markers should be removed through a process of member checking in which the researcher reviews each interview with the respective participants to ensure correctness of the data and privacy of the participants. Once this is completed, the data can be made available to the larger research group. Finally, in the third stage when the data has been analyzed and thematically organized into findings, the access can expand to the First Nations community (including the Chief and Council) and to the larger research community.

❖ KORI needs to incorporate a written contract in which the details of the community's and the researcher's concerns about the appropriate use of raw data and finalized research results could be specified and subject to arbitration if necessary. Ideally, the contract should be based on the consent of the participants in terms of whether their personal raw

data will be stored with the researcher or the community and whether this data should be archived or destroyed.

❖ KORI should necessitate regular meetings with various stakeholders to discuss the compilation of the data following the completion of the study. When it appears that one of the stakeholders disagrees with an interpretation of the data, he or she should be invited to discuss their concerns as an addition to the main data. Then as a group, the stakeholders can decide whether this new information or interpretation should be adopted as part of the final results. An effective and efficient way to facilitate this process is to pre-assign one representative from each stakeholder group to participate in regularly scheduled meetings through on-line discussions or videoconference until the project is completed.

❖ To reduce the cost of involving an intermediary organization, KORI should decrease the number of intermediaries involved in the process. Rather than having a staff member accompany the researcher, the researcher should establish a relationship with the community contact and community-based researcher either during an initial visit to the community or over videoconference. This way, the researcher is familiar with faces and places in the community upon arrival thus eliminating the need for, and costs associated with, an on-site KORI employee.

❖ KORI must create standardized research proposal forms and contracts for conducting research in KO communities so that expenditures for administration in terms of both time and money can be further reduced.

Recommendations for Researchers

❖ Researchers need to understand that cultural awareness, knowledge, and skills are a necessity when establishing a relationship with a First Nation. Researchers need to observe cultural protocols when approaching a community to explore their interests. The first of these protocols is that the researcher is responsible for consultation with appropriate community representatives (in most cases, the Chief and Council) to express interest of research.

❖ The researcher should present community representatives with the scope, purpose and usefulness of research and should ensure that this process is adequately budgeted for in the research funding application. It is recommended that researchers account for community-based expenses in their budgets as the community has the right to be compensated for any expenses accrued during the research process such as research assistants, translators, travel and use of facilities.

❖ Adequate financial compensation must be paid to First Nation co-workers, assistants and participants of the research where time is required to be spent outside of normal and personal activities.

- ❖ Researchers wishing to conduct research in the First Nations must take responsibility for speaking with REB's to ensure a compromise between institutional and First Nations ethics is achieved**.**

- ❖ Before commencement of the project, it is necessary for researchers to visit the community and familiarize themselves with the setting by volunteering at local organizations, participating in community events and excursions, attending workshops and conferences. It is essential for researchers to take the time to familiarize themselves with the research setting and to develop a relationship with the community. This helps to facilitate entry on the basis of mutual trust and respect; especially in First Nations, where communities have been abused by academic institutions, the government and other research organizations.

- ❖ Researchers need to understand that relationships of trust and respect are the foundation for ethical research practice. This requires a great investment in time, self-disclosure, valuing differences as well as genuine caring and concern for the community as well as devolution of power before discussions about research can proceed.

- ❖ Researchers should facilitate one or more community meetings to explain the research goals and the potential risks and benefits to the community.

- ❖ Researchers should also inform the community at every stage that participation in the study is based on individual volunteers and that collective consent in support of a research project constitutes the willingness to promote the research not a commitment of individual participation.

- ❖ Methods of research should be negotiated, agreed upon and stated in a written contract signed by each party. If there any changes are to be made, these should be renegotiated with the community before implementation.

- ❖ When conducting research in First Nations communities, the use of a participatory action research (PAR) approach is strongly recommended as it contributes to a balancing of the historical record in a First Nations voice, it increases the chance of development effectiveness and longevity, and the methods are consistent with First Nations values of decision-making as a collective.

- ❖ Building capacity for the community as part of the research methodology, including data collection, analysis and dissemination should also be negotiated in participatory process.

- ❖ Researchers should consider ways to ensure maximum involvement of the of community members in the planning, negotiating and carrying out of the project and in the presentation of outcomes.

- ❖ Community access to benefits should also include capacity and community development components such as training, education, programs and services. However, there needs to be clarity and agreement between communities and researchers about what capacity and

community development actually means in terms of its application and impact on communities.

❖ In obtaining individual and community informed consent, researchers should clearly identify sponsors, purposes of the research, sources of financial support and investigators responsible for the research.

❖ In obtaining informed consent, researchers should explain the potential benefits and risks of research, including the environmental, financial, legal, physical, psychological and social impacts of study on individuals and on the community.

❖ The informed consent of participants in research should also be obtained for information-gathering techniques to be used, (audio or video recordings, photographs or physiological measures) for the uses of information gathered from participants, and for the format in which that information will be displayed or made accessible.

❖ No pressure or coercion should be applied by researchers to obtain consent for participation in a research study.

❖ An individual or community should reserve the right to withdraw from the research at any point.

❖ Researchers should observe the normal proprieties with respect to personal privacy and practices such as concealment should be avoided.

❖ The manner in which confidentiality will be maintained should be fully explained, understood and agreed in advance by the people involved with the research before it is implemented.

❖ If confidentiality cannot be guaranteed, the participant must be informed of the possible consequences before becoming involved in the research.

❖ The ownership and dissemination of research results, including the allocation of rights between the researcher and the sponsoring agencies, should be clarified by the research in the initial negotiations with the community.

❖ During the initial consultations, researchers should negotiate with the community on the place where research results will be who receives the results, how many copies, in what format and where they will be deposited.

❖ Researchers should undertake continuous consultation and negotiation both during and after the project in order to maintain an ongoing relationship with the community. It is important for researchers to take note of this feedback and listen to the strategies and methods that have worked in their community to foster strong research partnerships in the past.

❖ When appropriate, a return visit that is planned and budgeted for should be made by the research to review and discuss the research results with community members.

❖ Subject to requirements for confidentiality, publications should acknowledge everyone who contributes to the research.

❖ In terms of publication, the cases where it is sought, it is recommended that the researchers collaborate with community representatives to write the manuscript. Co-authoring can be valuable as it provides the opportunity for a myriad of perspectives which can enrich the research outcomes.

❖ When manuscripts are not co-authored, representatives should reserve the right to review the drafts prior to publication in order to ensure that the integrity of the community and its constituents are protected.

❖ In the case where the community representatives completely opposes the publication of research results, the researcher should not publish the results except for providing summaries to academic and funding agencies where continued sponsorship necessitates progress reports.

❖ If funding permits, researchers should employ an (intermediary) organization with links to the communities to be responsible for ensuring that all stakeholders contribute to the research process in an ethical and culturally-appropriate manner.

Recommendations for Research Councils

❖ Research councils should encourage researchers, other funding bodies and institutional ethics committees to adopt a code of ethics for all research of interest to First Nations people.

❖ Research councils need to acknowledge First Nations perspective in all aspects of research ethics processes; from the development of guidelines, to implementation and monitoring, as well as protecting the interests of the people in a way that is appropriate for the cultural context.

❖ Research councils need to allow researchers to follow the procedures for entry. Entry into the community, as identified by Johnson (1984) and Hutchinson (1985), consist of four steps: stopping, waiting, transition and entry.

❖ REB's without the help of required expertise may reduce ethics to a focus on procedures rather than on the substance of research. Thus, REB's could benefit from consulting community representatives, First Nations researchers or other experts familiar with research ethics issues relevant to the proposed research.

- ❖ If REB members do review protocols to be implemented in Aboriginal communities, they should demonstrate relevant knowledge on local practices, participatory and consensus-oriented decision making processes, and the history of research relationships with Aboriginal communities.

- ❖ Research councils should review the work of researchers who have outlined procedures for working well with the First Nation. Document and publish methodology issues so that other researchers and funding agencies can access and reference accurate information.
- ❖ Research councils should require researchers to assess the implication of their research for First Nations people by including relevant questions in the research ethics form.

- ❖ Research councils should ensure the establish a database of current research and research needs and organize a regular meeting of stakeholders, including representatives of First Nations organization, to review research and identify priorities.

Recommendations for Funding Agencies

- ❖ Funding agencies should be aware of the time needed to develop personal relationships with community members and should account for these expenses when providing funding.

- ❖ Funding agencies should ensure that priorities and selection process reflect First Nation priorities and needs as well as academic research agendas.

- ❖ Funding agencies should review its selection processes with the aim of increasing proportion of funds available in the area of First Nation studies.

- ❖ Funding agencies in the selection of projects to fund, should include reference to criteria such as relevance to First Nation communities, usefulness of outcomes and processes by which negotiations with the community are conducted.

- ❖ Funding agencies should consider the potential impacts of research, both positive and negative, during the selection and evaluation of potential projects.

- ❖ Funding agencies should require include in its application forms provision for demonstrating the applicant's personal preparedness, as distinct from academic preparedness, for working in a First Nation community.

- ❖ Funding agencies should direct the attention of an applicant to guidelines on community consultation and other matters relevant to research of interest to First Nations people.

- ❖ It should be the responsibility of the funding agencies to ensure that the guidelines on consultation have been observed prior to the release of funds to the researcher.

Concluding Remarks

Conducting research in marginalized and minority populations such as the First Nations, inherently involves a dynamic of power. As members of colonial cultures, researchers have traditionally held power in the forms of money, knowledge and expertise over their participants. Surging from this foundation of power, are other ethical issues of consent, confidentiality, research design and data ownership. Thus, there are a number of issues arising from this report that warrant further research. The nature of participation and its limitations requires critical examination within the context of power imbalances, and the use of participatory practice as a means of legitimizing external interventions must be addressed in the context of participation as rhetoric or reality. Is it truly possible to achieve a balance of power between researchers and communities? Is it possible to ensure that participatory practice results in genuine power sharing? Where does the control of the research process actually rest? What are the ramifications of knowledge appropriation by both communities and outside researchers? What are the mechanisms for addressing power imbalances in the production of knowledge with the First Nations communities? Furthermore, what are mechanisms for addressing power imbalances within the community itself and assuring that some community interests are not being served at the expense of others? What are the implications for integrating capacity development into all research?

Although these questions remain, this report demonstrates that negotiation is a key concept for addressing issues of research, particularly power imbalances, with First Nations people. The research itself must become relational, if it is to succeed in terms of fulfilling all parties' interests. This is true, whatever the subject matter, and requires that all research projects be socially situated and collaborative while maintaining the highest ethical standards. Although

REB's are in place to ensure that the ethical standards of researchers are maintained, these standards were developed from the perspective of the dominant culture. Thus there is a need for REB's to re-valuate, re-develop and re-define what high ethical standards are in a cross-cultural context. At the same time, community-researcher partnerships are not without their challenges. Researchers must balance professional advancement with the goals of the larger community. Therefore, it is important to discuss differing values, world views and ethical practices when initially developing partnerships so both parties can enter the collaboration with a clear sense of the eventual outcome of the partnership. A community-based partnership incorporating an ongoing process of communication and consent offers and ethical solution that is mutually beneficial to both the researcher and the community.

With respect to health, greater disparities exist for the First Nation peoples in comparison to any population in Canada. Culturally competent research requires an understanding and application of Aboriginal paradigms of health, knowledge, science, and research. This understanding must be turned into proactive support from Canadian researchers, academic, and government institutions that undertake health research, and the financiers of such projects. Dominant-culture researchers following conventional paradigms can limit the possibilities to perform research with Aboriginal people in a more culturally competent manner. Training more First Nation researchers who are well versed in their own cultural paradigms of knowledge and research, who have the skills and knowledge of Western scientific inquiry, and who can bridge the science of both the dominant and the Aboriginal culture is necessary.

In conclusion, First Nations communities still remain marginalized from basic services enjoyed by non-First Nations peoples and the responses to requests for more community-based services with appropriate programs have been grossly inadequate. Thus community-researcher

partnerships in the First Nations are likely to increase in the future, but their establishment must be guided by principles that create mutually beneficial and reciprocal relationships. This will also require the support of the federal government and funding agencies to phase out the business model for negotiations (cheapest deal at the cheapest cost) to a model based on consultation and community development where there is an emphasis on the transfer of skills, sharing of wealth and resources, and the creation of sustainable economies. There is immense potential for social change and improvements in the quality of life for First Nations by combining the skills, knowledge and expertise of communities and researchers. This report, through the documentation of stakeholder perspectives, hopes to provide First Nations communities, non-First Nations researchers, intermediary organizations and research ethics boards who are interested in developing community-research collaborations, either for practice or for scholarship, with ideas and directions to avoid pitfalls and potential problems in developing successful partnerships as well as increase the benefits associated with collaborations and to bring about social change.

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Appendix 1: KORI Community Consultation Guidelines (KORI, 2005)

`Community Consultation Standards`

The objective of the community consultation guide is to prepare researchers to visit a KO affiliated community. It is a compilation of experiences and recommendations offered by community members and leaders, KO staff and community–based researchers. The guide has eight sections:

1. Objective
2. Preparation - an outline of the steps involved in preparing a community visit.
3. Resources - discusses the use of ICT tools.
4. Ethics – describing the collection and use of data.
5. Community Visit Itinerary – list of important meetings.
6. Ongoing Engagement – describing the importance of maintaining relationships.
7. Success – how to know if the visit was successful.
8. Budget – Appendix F is a budget for a sample community visit.

Please note that the guide is a work in progress and the suggested procedure may change over-time and between communities. The community contact is the best person to consult to ensure the visit is successful (low impact and highly beneficial to the community). Community visits should be a rewarding and learning experience for researchers and community members alike.

Objective

The research objective should be inline with the following: To visit a First Nation community to meet with leaders, elders, program workers, youth and community members to improve First Nation access to information and research capacity that will improve programs and services and ultimately improve quality of life in the community.

The researcher is in the community to generate discussion, get people thinking and talking about how to improve services and programs. The researcher is not there to extract information to provide to an outside source.

Preparation

The following steps are recommended for preparation of a community visit. Refer to Appendix A for a timeline of the steps. Appendix B provides a flow chart including all the necessary steps involved in planning a community visit.

Chief and council

Firstly, call the chief and ask permission to visit the community. Explain the reason and duration of the stay. If approved, the chief will indicate a community contact. Fax the Chief and council a one-page info sheet explaining who you are representing, the purpose and expected outcome of the visit.

The Chief is the first contact; permission must be obtained from the leadership before the visit can take place. If the chief is unavailable, the deputy chief or councillor may be contacted. However, if the councillor recommends that the chief be ultimately consulted, follow their advice.

Community Contact

Second, call the Community Contact (CC) and fax them an info sheet. The CC is usually a person overseeing the topic of interest. Ask the contact about including a Community–based Researcher (CBR).

The community contact will be a worker involved in local programs pertaining to the topic. The worker may be too busy to organize the visit, however, it is ideal to have the CC present for the community meeting. The CC will be interested in the results of the visit and how they can be used to benefit the community through their work.

Community-based Researcher

Where applicable, contact the CBR to see if they are available prior to and during the visit. Fax a negotiable contract to the CBR and discuss the deliverables. Keep in contact with the CBR for updates and to provide additional information and support when required.

The CBR acts as the link between the researcher and the community. The researcher is working in partnership with the First Nation and the CBR as a contact. The researcher

should involve the CBR in all aspects of the research to improve the local capacity. The CBR may also provide transportation, translation and act as a guide. They are usually younger community members who are knowledgeable, flexible, fast learners and can help the researcher avoid any cultural mistakes.

The CBR will complete the preparation work including planning and promoting the community meeting, deliver surveys, set-up meetings with elders, and may even take the researcher on a tour of the community. The relationship with the CBR is vital to the success of the visit. KORI's objective is to work with CBRs at every opportunity to most effectively carry out research. Attached in Appendix C is a sample CBR contract and deliverables.

Resources

When visiting KO affiliated communities, researchers are encouraged to take advantage of available communication resources. IP telephones are available in offices and some homes allowing networked calls to be made with no long distance charge. A broadband internet connection is also available in the communities at varying speeds depending on demand and weather. Video Conferencing is widely used. Adding a visual aspect to communication helps to build relationships faster. The E-Center is a local public internet access point and also has a VC unit.

Ethics

OCAP Principals

The term OCAP (Ownership, Control, Access and Possession) was coined by the National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey. OCAP is used to make decisions regarding why, how and by whom information is collected, used and shared for research, evaluation and planning purposes.[2] It can also ensure that individual and community privacy is protected in a way that is appropriate to the First Nations language, culture and beliefs. It is used to strengthen the gap left by the Privacy Act and the Access to Information Act that apply to individuals but not to overall community issues.

Ownership: The First Nation owns the cultural knowledge, information and data.

Control: First Nations people, their communities and leadership have control of the research and information processes.

Access: The First Nation has access to the information collected and resulting documentation.

Possession: The First Nation is in possession of the data collected and may distribute it according to agreements.

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[2] Research Tool Kit, National Aboriginal Health Organization (NAHO/ONSA) 2003.

Community Visit Itinerary

A three-day, two-night visit is ideal. For each meeting, refer to the consultation suggestions in Appendix D.

Meeting with Chief and Council

Upon arriving in the community, the researchers and CBR should go immediately to the band office to introduce themselves to the Chief and council. If necessary, prepare a presentation to outline the visit purpose. A discussion and question period will follow the presentation. The researchers will be asked direct questions regarding the purpose of the visit and benefit to the community. The leadership may express some frustration from being overly researched. The position of the researcher should be that they are there to listen to the community and do their best to record suggestions and comments in order to improve local programs and services and ultimately the quality of life for community members. (If this is not the objective, re-examine the visit purpose). Be attentive to the amount of time that the leadership has. Leaders may suggest several community members that will be valuable to visit.

Meeting with community workers

As time allows, the researcher should visit all service centres in the community (Health Centre, Clinic, Community Hall, School, NAPS Office, Youth Centre, KiHS Building, E-centre, Telehealth Office, etc) to meet with community workers. It is important to tour the community centres for three reasons: to understand how the community works, what resources are available, and to meet people. When the researcher is seen visiting and touring the community, they are seen as more approachable and transparent. People are affected by all the working parts of the community, it is important to be familiar with more than just the research topic. These visits can be unannounced unless a formal meeting is required.

It is also important to spend some time at the local store where the researcher is visible and can meet many other people.

Meeting with Elders

Elders are valuable leaders in the community and their input provides significant contributions to the visit. Elders share a passion for their communities. They are an invaluable source of knowledge and are widely considered as holding communities together.

A translator must accompany the researcher, as many Elders prefer to speak their native language. Meeting with Elders in their homes demonstrates respect and helps to make them more comfortable. Meetings with Elders must be prearranged (same or pervious day). Elder discussions may only require one opening question. Elders may speak at length in response to a question, giving anecdotes and examples. It is respectful to bring a small gift for the Elder.

Meeting with Youth

Youth are an important part of the community. It will be difficult to attract youth to a formal meeting, however they can be better reached in informal settings. Develop relationships with youth by hanging out at the local store or participating in sporting events. Do not pressure youth to speak; they may share if they wish to. In a recent trip, KORI's researchers asked the council about a program for youth, after providing some suggestions, the comment was made, "make sure you ask the youth what they need."

Sharing Circle or Community Meeting

The sharing circle is used to invite a sample of the community to discuss a topic of interest (similar to a focus group). It is a culturally appropriate method that communities use primarily for healing purposes. Each participant contributes to the circle as a listener and a speaker. The discussion is not directed at the facilitator but to everyone in the circle. Participants find the discussion most rewarding when they are given an opportunity to share and learn from their peers. The sharing circle format can be found in Appendix E. It may be advised that the meeting not be called a sharing circle even if it is designed that way, the title may scare some away.

When the topic is less personal, it may be more appropriate to have a community meeting rather than a sharing circle. The sharing circle may intimidate participants because it is usually associated with personal sharing. A community meeting is more of an open discussion, with a presentation and subsequent discussion. It is more of a dialogue between the researchers and participants. The meeting must proceed even if one person attends. That one person should be treated equally important as a larger group.

Ongoing Engagement

Following the visit, the draft results should follow for review by pertinent KO staff and community representatives. Work with contacts to edit and complete the results of the visit. Provide a copy to the contacts and make it available online in a clear, easy to read and access format. A presentation may complement the report if it is lengthy. Brian Beaton, the K-Net Services Manager promotes ongoing engagement and says that a community visit should be a continuum of engagement. The relationship with contacts and exchange of ideas should continue beyond the visit, resulting in future projects, benefits and relationships.

Success

Tina Kakpetum Schultz, a KO mental health worker says; "success is described as at least one elder coming to the meeting." Success is developing a relationship with the people you meet. It also occurs if the community should feel that they have benefited from the visit and that they were shown respect. Hopefully the outcome will be to improve access to information that will help to improve programs and services and ultimately quality of life in the community.

Budget

Appendix F suggests a budget for a sample community visit. It describes the cost to visit Keewaywin FN, and an additional community. The cost estimates are applicable for most Northern Ontario communities. Fort Severn FN is an exception. Due to the distance from urban centers, airfare will be double the estimated amount.

Appendix A

Consultation Timeline

#	Action
1	Call Chief
2	Fax Info sheet to band office
3	Call CC
4	Fax Info Sheet to CC
5	Call CBR
6	Negotiate Contract
7	Get updates
8	Community visit
9	Follow-up
10	Submit results for editing
11	Submit final results
12	Ongoing Engagement

call Chief   call CC   call CBR   community visit   results   engagement

fax info   fax info   negotiate contract   follow-up   final results
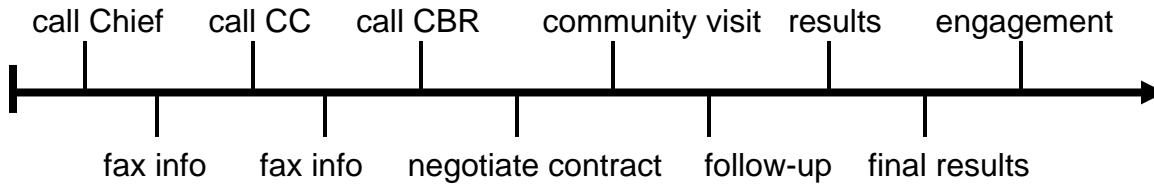
Appendix B

Community Consultation Flow Chart
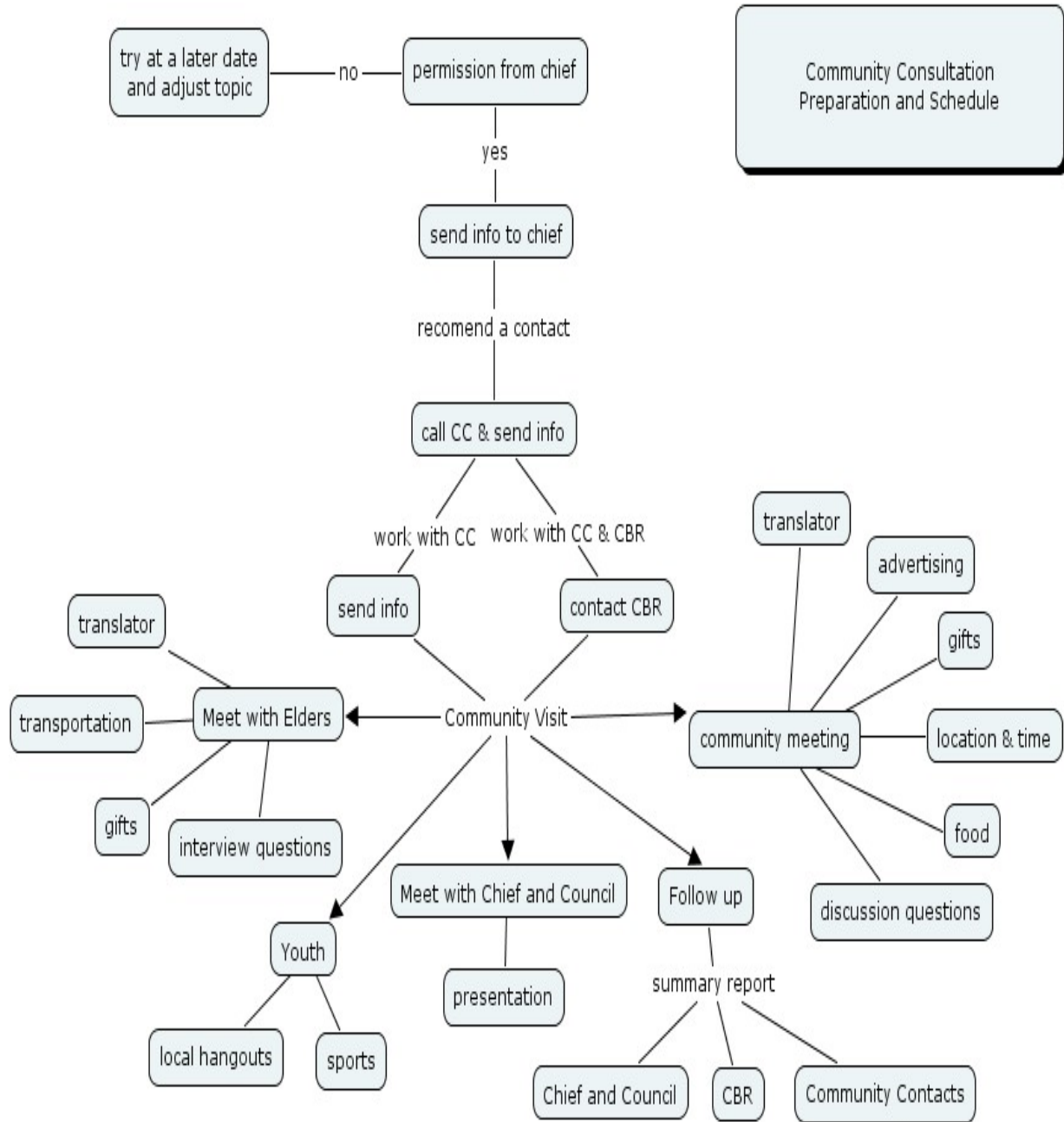
Appendix C

Sample Community-based Researcher Contract

Deliverable	Days	Rate $100/day	Tasks	Completed
Deliverable 1 Community visit	3		1. Be available during KORI's three-day visit to accompany and assist the KORI researchers to the E-centre, school, band office, nursing station, elders houses and to translate when necessary.	❑
Deliverable 2 Survey	2		2. Meet with KORI by VC	❑
			3. Print 50 surveys	❑
			4. Visit homes and fill out surveys with participants	❑
			5. Collect 50 completed surveys	❑
			6. Store the surveys until KORI arrives to collect them	❑
Deliverable 4 Community Meeting	2		7. Advertise the community meeting (poster provided)	❑
			8. Book room and refreshments for 20 people for a community meeting	❑
			9. Join KORI at the community meeting	❑
Deliverable 5 Final Interview	-		10. Meet with KORI for a final interview	❑
Total	7	$700		

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Appendix D
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Community Visit Suggestions

Have a positive attitude, be open and approachable – be transparent and available to talk and meet with people. It is important that the researchers are seen at the store, visiting community locations, talking with people and playing with youth.

Be flexible, scheduling will not follow your plans – transportation, office procedures and work schedules are not regimented. There are many exretminating circumstances that will change the schedule. There is only one flight per day between Keewaywin and Red Lake (the closest urban centre). Flights are frequently delayed or cancelled. During KORI's past two trips to Keewaywin there were flight problems. The first trip, flights out were cancelled for two days. During the second trip researchers had to take a boat for the 1-hr ride from Keewaywin to Sandy Lake FNs because the air route could take more than one day.

Do not interrupt people when they are speaking – people may talk at length in response to one questions but never or shorten their time to speak. There was a recent session with many people, and the circle was halfway finished when someone was talking for over 30 minutes. The researcher looked around the circle and no one was fidgeting, restless or even distracted. Everyone was being respectful, attentive and listening. The researcher did the same and let them finish.

Clearly word questions - particularly wording for surveys, interview and discussion questions. A recent when a survey question was not clear and someone asked, "what does this questions mean?" After explaining it more clearly, they replied: "well why didn't you just say that then?"

Be patient and understanding - there will always be a cultural gap and community members will be patient with the researcher's ignorance. The researcher should not force an agenda.

Show respect – treat others as you would have them treat you.

Building relationships is the number one priority.

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Appendix E
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Sharing Circle Format

1. Obtain talking stone
2. Designate a recorder and facilitator for the sharing circle.
3. A prayer is said to open up the circle
4. Ask for permission to make transparent notes on a visible flip chart*
5. Included the flip chart in the sharing circle
6. Recorders will obtain consensus on what was written before moving on
7. A talking stone is passed around the sharing circle
8. The person with the talking stone will introduce themselves and share their thoughts feelings and experiences on the theme of the question
9. End sharing with a thank-you and pass the talking stone to the next person
10. Close the circle with a prayer

*Based on the sensitivity of the discussion topic, recordings may not be allowed.

Guiding Principles:

1. We are all equal.
2. No judgments upon another or upon ourselves.
3. Remember to use the seven gifts: love, sharing, honesty, trust, humbleness, bravery and wisdom in the circle.
4. What is said within the circle stays within the circle unless it is agreed ahead of time to put it on paper for documental purposes.
5. Respect each other's right to speak without interruption. The person holding the stone has the right to speak as long as he/she wishes. You don't have the right to speak if you are not holding the stone.
6. A person can pass the stone if they don't have anything to say.
7. Seek healing by sharing and understanding yourself, not trying to get others to change for you.
8. Nothing is coincidental; there are reasons for every experience.
9. Offer your support, not your pity when healing comes to others within the circle

Appendix F

Community Consultation
Sample Budget

Expense	Rate	# Days	Keewaywin	Additional Community 1
Travel				
Airfare (round trip)				
Thunder Bay-Red Lake	$ 450.00		$ 450.00	
Red Lake-Keewaywin FN	$ 450.00		$ 450.00	
Inter Community	$ 180.00			$ 180.00
Excess Baggage 2	1.07/lb		$ 100.00	
Mileage 3	0.45/km			
Sub Total			$ 1,000.00	$ 180.00
Incidentals				
Private 4	$ 50.00			
MTO 5	$ 110.00	2	$ 220.00	$ 220.00
Food	$ 70.00	4	$ 280.00	$ 140.00
Taxi	$ 20.00	4	$ 80.00	
Sub Total			$ 580.00	$ 360.00
Consultation				
CBR 6	$ 100.00			
Survey		2	$ 200.00	$ 200.00
Community Meeting		5	$ 500.00	$ 500.00
Food 7	$ 100.00		$ 100.00	$ 100.00
Gift 8	$ 200.00		$ 200.00	$ 200.00
Promotion 9	$ 20.00		$ 20.00	$ 20.00
Survey Prize 10	$ -			
Sub Total			$ 1,020.00	$ 1,020.00
Total				
			$ 2,600.00	$ 1,560.00

Notes:

1 Cost to visit an additional community

2 Baggage limit is usually 70 lbs. Including an engagement gift and computer equipment will result in excess baggage costs

3 Driving is not recommended due to distances and road and weather conditions

4 Private accommodations in the community may only be used following approval by the Chief

5 The Ministry of Transportation of Ontario provides accommodations in each FN and is located at the airport

6 Community-based Researcher

7 Bring fruit from an urban centre and buy food for 20 participants in the community

8 Spend $20 per person

9 Printing for poster and flyers

10 The survey requires a prize, which is usually donated

Appendix 2: Consent Procedure

University of Guelph
Statement of Verbal Consent

This statement will be reviewed in consultation with the KORI Research Team. It will read in the local language (Oji-Cree) before beginning any data collection effort takes places in the community. KORI will be encouraged to share the document before the researchers arrive in the community if is appropriate.

Project Title: Exploring Key Stakeholder Perspectives for a Collaborative First Nations Health Research Protocol (Establishing open communication between communities and health researchers so that research can be sensitive, relevant and respectful to the First Nations).

Facilitator: Aliya Pardhan

Before we talk about your ideas and experience with health research, my University and KORI ask that every person I interview be informed of the following:

1. You are to be in full control of this interview and you may end it at any time. If you chose to end the meeting, you do not have to provide me with any explanation.

2. This interview is voluntary and you are under no obligation to answer any questions that you do not wish to answer.

3. No consequences of any kind will result from your ending this interview or from choosing not to answer questions.

4. All that is discussed in this interview will remain completely confidential. Confidentiality will be maintained through the use of a reference number for each participant. The transcribed interviews will be kept with myself until a summary of community input has been created. This summary will be completed within the next 3 months. Once the summary is completed, all transcribed documents will be shredded and the summary will be given to KORI. The information you do provide will be used to develop more respectful research activities with First Nations. Part of this information will also be used in my thesis work for the University of Guelph.

5. You may ask to review the content of this interview at any time.
If you agree to an interview, I will ask that you inform me of your agreement at the time of our meeting.

Appendix 3: Poster for Community Meeting (KORI, 2005)

Do you want to improve research in your community?

Come and discuss how to improve research at a Community Meeting!

Date: February 6th, 2006
Location:
For more info contact: Connie Thomas

SNACKS   Free T-Shirt

Many researchers and contractors have visited Fort Severn over the last few years to conduct research regarding the school closure, health issues and economic development. KORI would like to ask communities how researchers can do a better job to serve communities when they come. Community members can assist in developing a research standard for community consultation by telling us what experiences they have had with researchers and what can be done to improve the relationship. The standard will then require researchers to follow the recommendations of community leaders and members when visiting their community. It will ensure that the communities benefit directly from the research and that research be conducted in a respectful manner. This is a great opportunity for you to shape future research methods in the North.

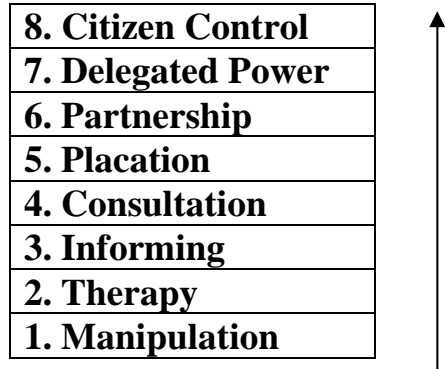KORI will be finding out what you think through the following:

- Meeting with Chief and Council
- Visiting with Elders
- Meeting Community Health and Education Workers
- Meeting Youth
- Community Meeting

Appendix 4: A Framework for Judging Trustworthiness Criteria (Pretty, 1994)

1. *Prolonged and/or Intense Engagement Between the Various Actors.* For building trust and rapport, learning the particulars of the context, and to keep the investigator(s) open to multiple influences.

2. *Persistent and Paralleled Observation.* For understanding both a phenomenon and its context.

3. *Triangulation by Multiple Sources, Methods, and Investigators:* For cross-checking information and increasing the range of different people's realities encountered, including multiple copies of sources of information, comparing the results from a range of methods, and having teams with a diversity of personal, professional, and disciplinary backgrounds.

4. *Analysis and Expression of Difference.* For ensuring that a wide range of different actors are involved in the analysis and that their perspectives and realities are accurately represented.

5. *Peer or Colleague Checking.* Periodic review meetings with peers not directly involved in the original information was constructed and analyzed. Without participant checks, investigators can make no claims that they are representing participants' views.

8. *Reports with Working Hypotheses, Contextual Descriptions, and Visualizations.* These are "thick" descriptions of complex reality, with working hypotheses, visualization, and quotations capturing people's personal perspectives and experiences.

9. *Parallel Investigations and Team Communications.* If subgroups of the same team proceed with investigations in parallel using the same system of inquiry and come up with the same or similar findings, then we can depend on these findings.

10. *Reflexive Journals.* These are diaries individuals keep on a daily basis to record a variety of information about them.

11. *Inquiry Audit.* The inquiry team should be able to provide sufficient information for a disinterested person to examine the processes product in such a way as to confirm that the findings are not a figment of their imaginations.

12. *Impact on Stakeholders' Capacity to Know and Act.* For demonstrating that the investigation or study has had an impact, including participants having a heightened sense of their own realities, as well as an increased awareness and appreciation of those of other people; the report itself could also prompt action on the part of readers who have been directly involved.

Appendix 5: Ladder of Citizen Participation (Arnstein, 1969, p. 217)

8. Citizen Control
7. Delegated Power
6. Partnership
5. Placation
4. Consultation
3. Informing
2. Therapy
1. Manipulation

Appendix 6: Submitting Research for Review: The Application Process
(University of Guelph, 2006)

Section A – General Information

A.1 Title of the Research Project

The title of the Research Project should describe **as briefly as possible** the area or focus for which ethics clearance is sought. If the project is funded, the title of the project should be identical to that on the corresponding grant application.

A.2 Investigator Information

Please provide full information for all those involved in the project. Faculty, staff, or students of the University of Guelph can be identified by department. Addresses should be provided for off-campus personnel. Graduate students who are applying for ethical review of their thesis projects are considered Student Investigators. **The supervisor must assume the role of Principal Investigator.**

A.3 Proposed Dates of Commencement and Completion

The commencement date should be the date the researcher expects to actually begin interacting with human participants (including recruitment). The completion date should be the date that the researcher expects that interaction with human participants, including any feedback or follow-up, will be complete. DO NOT use the date that your entered your degree program as the date of commencement. Extensions to the stated completion date can be requested by submitting a Change Form.

A.4 Location

If the research is not taking place at the University of Guelph, please be specific about where it will be located (e.g. at the participants' home; South Western Ontario farms; Nigeria). If within the University of Guelph, please indicate a particular laboratory (if applicable).

A.5 Other Research Ethics Board Approval

If the application has been reviewed and approved by another institutional research ethics board, the application may be eligible for expedited review - please provide a copy of the approval. If another Research Ethics Board will be asked for approval, please advise the University of Guelph Research Ethics Board of the outcome of that application. **Please provide a copy of the approval when it is received.**

A.6 Level of Project

Please indicate the level of the project. More than one level can be indicated.

A.7 Funding of the Project

Indicate if the project is currently funded. Specify the complete title of the funding source (e.g. not just NSERC, but NSERC Discovery Grant). If the funding source changes, or if a previously unfunded project receives funding, you must submit a Change Form to the Research Ethics Coordinator. Changes of funding sources may require submission of a new application.

A.8 Conflict of Interest

The expression "conflicts of interest" used in an ethical sense refers to conflicting obligations or influences confronting an individual in the course of a relationship or activity that has some moral content. Conflicts of interest may or may not involve financial or monetary interests. Examples of conflict of interest include financial benefits such as remuneration, intellectual property rights, rights of employment, consultancies, board memberships, share ownership, or stock options received by the researcher, members of the research team, and/or their partners or immediate family members. The central issue is that individuals engaging in conduct that has ethical dimensions are drawn in two directions at once in such a manner that their judgment may be affected, or their motives may be open to question.
In order to assess the likelihood of a real of an apparent conflict of interest which must be disclosed, researchers should consider:

- Whether an outside observer would question the ability of the individual to make a proper decision despite possible considerations of private or personal interests;
- Whether the public would believe that the trust relationship between the relevant parties could reasonably be maintained if they had accurate information on the potential sources of conflict of interest.

If a conflict of interest appears to exist in a particular project, the Research Ethics Board will make recommendations which may include, but are not restricted to:

- Requiring that the researcher publicly disclose the conflict of interest, possibly in the context of the informed consent document;
- Monitoring the research by independent reviewers;
- Modifying the research proposal or plan;
- Disqualifying the investigator from a portion or all of the research;
- Requiring that the researcher divest him or herself of the financial interest;
- Requiring the researcher to sever the relationship with the sponsor.

Conflict of Interest Policy
Researchers and Research Ethics Board members must disclose actual, perceived or potential conflicts of interest. [TCPS, Article 4.1]

At the commencement of the free and informed consent process, researchers shall provide prospective subjects with information pertaining to the possibility of commercialization of the research findings, and the presence of any actual or potential conflict of interest on the part of the researchers, their institutions or sponsors. [TCPS, Article 2.4 (e)]

The University of Guelph's Faculty Policy defines conflict of interest as follows:

Each faculty member has a responsibility to ensure his/her activities are arranged so as not to conflict or interfere with his/her overriding commitment to the University (see also Section C, Part 3 (External Remunerative Activities). There are two broad categories of potential conflict. A conflict of interest is a situation in which influence or knowledge gained by virtue of position might be improperly used to effect financial gain or advantage for oneself or one's associates. This includes the use of information not in the public domain acquired as a result of a faculty member's University-supported activities (unless the individual has proprietary rights, usually enforceable through copyright or patent). A conflict of commitment is a situation in which a faculty member's outside private or professional interests interfere with his/her obligations to the University. Conflicts of interest and commitment should be handled in a careful and open fashion in order to avoid situations that may not be in the best interests of either the faculty member or the University. [Faculty Policies, Section C: Part 1, 1.03]

A faculty member or librarian has a responsibility to ensure that conflicts of interest, wherever and whenever they arise, are identified and disclosed to the next person in the line of authority within the University so that the conflict situation will be addressed and, if possible, accommodated.

A conflict of interest may arise from, among other things, family relationships, current or past spousal or common law relationships, or financial relationships. [Faculty Policies, Section C: Part 1, 1.04]

Section B – Summary of Proposed Research

B.9 Rationale

Please keep this section brief, and deal only with the research for which you are seeking ethics clearance. Do not attach thesis proposals.

B10. Methodology

The best way to approach the methods section is the put yourself in the position of your participant. What exactly are you going to experience from the time you begin the project until the end? Keep it simple and brief.

B.11 Experience

Researchers are required to cite their experience and training in the type of research being conducted. If the expertise of a technician or a physician will be employed (whether paid or unpaid), please attach a current CV showing that the individual is suitably qualified for the work being done.

B.12 Participants

TBA

B.13 Recruitment

TBA

B.14 Compensation

If participants are to be compensated, the details of the compensation must be provided. The compensation must be commensurate with the risks of participation and must not be so significant that they could be perceived to be an inducement to participate. Details must be provided concerning what the impact of withdrawal from the study will have on compensation. Ideally, compensation should be prorated. [TCPS, C1]

Section C – Description of the Risks and Benefits of the Proposed Research

The RESEARCH ETHICS BOARD will determine whether the risks of the research are proportionate to the anticipated benefits (if any) to the human participants and the importance of the knowledge that may reasonably be expected to result. Foreseeable harms should not outweigh anticipated benefits. [TCPS, Section C]

C.15 Risks

Risks may include:

- Physical harm
- Psychological or emotional harm
- Injury to reputation or privacy
- Breach of any relevant law
- Deception

The Research Ethics Board is concerned about risks to:

- The participants involved
- Clearly identifiable third parties

The researcher should be able to provide examples of how risks will be minimized and how they will be managed throughout the conduct of the study.

The Research Ethics Board will also consider the professional qualifications and resources of the research team in its assessment of risk.

C.16 Benefits

The proposed benefits should be realistically described, in relation to the participants, the researcher, and in relation to the scientific community and society as a whole. Types of answers that might be appropriate include:

- Student researcher: increase understanding of research methods and cognition;
- Participants: learn about research methods; may have questions answered about their situation; knowing that their experience and knowledge is being valued and recorded; no direct benefit.
- Scientific community: This study may provide insights into how, when etc…; or none, I will be replicating a well-known phenomenon;
- Society: better understanding of… may lead to effective techniques for enhancing/training, treating, etc.

Section D – The Informed Consent Process

D.17.a Informed consent is the cornerstone of participant protection and is the process whereby a choice is made:

- By a competent person
- On the basis of adequate information concerning the nature and foreseeable consequences of the research and all available alternatives; and
- Without controlling influences such as "force, fraud, deceit, duress, over-reaching or other ulterior form of constraint or coercion" [Nuremberg Code]

The informed consent process is different from the consent form. It involves meeting with a potential subject, finding out whether he or she is capable of giving consent, and discussing the purpose, risks, and benefits of participation. Obtaining informed consent is not just giving a prospective subject a consent form and getting it signed. Researchers should strive to convey information to subjects, not merely disclose it to them. If student researchers are to be involved in the consent process, they should be made fully aware of the ethical expectations involved.

With regard to written Information Letters and Consent documents, please refer to the guidance documents available:

- Instructions for Preparing Information Letters and Consent Forms
- Sample Consent Form

The written information should be designed to inform the research participant in order to permit him/her to make an intelligent, voluntary decision prior to participation in the study. For this reason

- The form should be written in a straightforward fashion, well-organized and succinc;
- Technical terms should be explained in simple language;
- The language should be grammatically correct with no spelling errors. ***Note: The Research Ethics Board is not responsible for editing the final copy of consent documents for grammar or spelling. Comments will only be made if the errors render the meaning questionable. Please check your document carefully—they are representing the University of Guelph to the public.***

If necessary, when English is not the primary language of the research participant, an interpreter must be provided to ensure that the participant has every opportunity to understand the details involved in participation.
Investigators have the option of using separate Letters of Information and Consent Forms or a combined Information/Consent document. The sample Consent Form is provided as guidance only. Investigators are free to design their own version. Participants must be provided with their own copy of the Letter of Information or the combined Information/Consent Form.

In presenting information, it is important to avoid characterizations of the research project that are in any way coercive. The language of consent forms, as well as the circumstances of recruitment, should attempt to ensure that potential participants have a genuine choice about their involvement. Consent should not be sought under conditions of emotional or physical stress, but rather, if at all possible, consent should be sought prior to the period of physical or emotional stress.

D.17.b Deception

Free and informed consent requires that subjects be fully informed about the purpose of the study before being asked to agree to participate. In some fields of research, in particular social/behavioural research, studies cannot be conducted without deception, concealment or covert observation. Such research may be approved by the Research Ethics Board, provided that at a minimum:

- The research involves no more than minimal risk;
- The use of deception is unlikely to adversely affect the rights and welfare of the subjects;
- The research could not be carried out without the use of deception, concealment or covert observation;
- Wherever possible, the subjects are provided with full debriefing subsequent to their participant which may involve a second written consent document;
- The research does not involve a therapeutic intervention.

[TCPS, Article 2.1(c)]

In addition, the researcher should provide the research ethics board with information specifically detailing the precise extent of the deception, concealment or covert observation. In some cases where deception is utilized, researchers should be especially careful to ensure that participants are

informed that they have the right to withdraw data obtained from them during the research without their knowledge or consent.

D.18 Consent by an authorized party

Sometimes the participants are not competent to consent. Competence means that a person is capable of making a morally and legally valid choice to participate in research. Competence is the measure of the ability of an individual to act or behave in certain situations. In the context of research, it means the mental ability to understand the nature and consequences of one's acts, so as to be fit to make informed choices concerning participation in research. Competence is determined by both the situation and the person's understanding of it. A prospective research participant may be incompetent in certain situations, but competent in others.
To be considered competent to make a valid choice, prospective research participants should be able to understand and appreciate:

- The nature and purpose of the research in question;
- Why they, as opposed to others, are being selected and asked to participate;
- The fact that the suggested intervention is for research purposes;
- The relevant elements of uncertainty about the procedure;
- What participation in the particular research project means for the participant;
- Whether nor not the intervention may provide any direct personal benefit to them;
- How the consequences of a decision to participate or not to participate will affect their own current and future lives;
- That they will be free to withdraw from participation at any time during the course of participation;
- That a decision not to participate or to withdraw from participant will not adversely affect them with respect to care, or in any other manner;
- Any conflict of interest on the part of the person recruiting the participants or conducting the study;
- The confidentiality of any records that identify the participant;
- For research that involves physical contact or physical activity, whether compensation or medical treatment will be available if the participant is injured and where to get further information about this;
- Who can answer questions about the research, including the principal investigator and a neutral third party who can explain the rights of research participants.

Evidence of free and informed consent by the participant should ordinarily be in writing (Consent Document)

D.19 Alternatives to prior individual consent

Where written consent is culturally unacceptable, or where there are good reasons for not recording consent in writing, the Research Ethics Board may allow the use of oral consent. The

alternative procedures used to seek consent must be well documented and this documentation must be described in the application. It is the responsibility of the researcher to justify why prior written informed consent is not appropriate for the research project being proposed.

In most cases, a written statement of the information ([Information Letter](#)) conveyed in the consent process, signed or not, should be left with the participant. Sometimes, researchers will use both documents during the consent process. Please note that the participant should ALWAYS receive a copy of each of these documents. It is imperative that the researcher clearly explain in the application how the alternative consent process will be handled and documented.

D.20 Participant feedback

It is recommended that researchers provide participants with the opportunity of benefiting from whatever knowledge is gained through the research process they have taken part in. This feedback can take the form (for example) of a debriefing session immediately following the project, a website which will list the research outcomes, an email discussing the research outcomes, or a printed submission of a scholarly paper. Participants should be informed in the information letter and/or consent form of how and when feedback will be available.

D.21 Participant withdrawal

Participants must be advised of their right to withdraw from the project at any time with no negative consequences. In the case of students, they must be assured that choosing not to participate, or withdrawing once the study has begun will in no way affect their standing in any course (with the exception of course credits for the Psychology Subject Pool). Participants should be clearly told how they should withdraw, if that is their choice. If, for some reason, participants will not be able to withdraw, this should be justified.

For surveys and questionnaires, participants must be informed that they are free to skip any question they do not feel comfortable answering. Ideally, this statement should appear at the top of each survey or questionnaire.

Section E – Confidentiality

Confidentiality refers to the legal and ethical obligation that arises from a relationship in which a person receives information from or about another. The recipient has an obligation not to use that information for any purpose other than that for which it was given.

Privacy is the right to decide the extent to which personal data that is not already in the public domain, may be disseminated.

Research participants have a right to privacy and researchers have a corresponding duty to treat private information in a respectful and confidential manner. When reviewing applications for approval, the Research Ethics Board should balance the need for research against infringements of privacy and invasions of privacy should be minimized as much as possible. The value of privacy of research participants is not absolute, some public interests such as protection of health, life, and safety may require infringement of the right to privacy, as may the type of research being

conducted; without access to personal information it would be difficult if not impossible to conduct important societal research in such fields as epidemiology, history, genetics, and politics.

Different cultures will value privacy in different ways and these values should be respected. The issue of privacy must be looked at from the cultural perspective of the participant, not the researcher.

As a general guide, the best protection of the confidentiality of personal information and records will be achieved through anonymity. Please note that anonymity can ONLY be assured when there is no way to match the research data with the participant. Coded data is NOT anonymous. Identifiable data should be coded at the earliest possible time. A minimum number of research staff, all of whom should be instructed about confidentiality requirements, should be involved. The consent of the participant should be obtained if at all possible prior to accessing personal records.

Researchers are responsible for ensuring the confidentiality of data on human subjects by maintaining such data in secure storage and by limited access to data to authorized individuals. Such security measures as locked offices, locked desks or file cabinets, password protected computers are appropriate. Be aware that data kept on laptop computers is at risk of loss through theft. Data must be kept secure from theft, copying, interception and/or casual release.

E.22.c

The research design must include procedures appropriate to securing the degree of confidentiality guaranteed to the research participant by the researcher, as outlined in the informed consent process.

E.22.d

Note that researchers must state how long they intend to keep research data of any form [field notes, tapes (audio or video), and questionnaires, for example]. They must also state how and when they plan to destroy this information or elucidate plans for long-term storage of the data.

E.22.e

There are cases for which anonymity and confidentiality are not appropriate to the research project nor sought after by the participant. The researcher must clearly state how participants will be advised of the degree of anonymity or confidentiality they can expect and consent to such disclosure and/or direct quotation must be obtained.

Section F – Monitoring Ongoing Research

F.23.a Annual Review

The TCPS requires the Research Ethics Board to monitor research on an ongoing basis. Like the initial review procedure, this ongoing review is proportionate to risk. In other words, the greater the risk, the more monitoring in required. It is the role of the researcher to suggest to the

Research Ethics Board what level of monitoring is appropriate—this should be done upon application. **At the very least, an annual report is required**. In addition, it is the responsibility of the researcher to inform the Research Ethics Board when the project concludes. [TCPS, Article 1.13]

In order to facilitate the submission of annual and completion reports, the Research Ethics Coordinator will send a notice to the researcher when one of these reports is due **It is imperative that the researcher submit the required report to maintain ethics clearance.**

F.23.b Adverse Events

Adverse events (sometimes referred to as SAE or serious adverse events) occasionally occur during the course of a research project. These are events which have unanticipated negative consequences or results which affect participants. **It is imperative that any event which has a negative consequence for a participant be reported immediately to the Research Ethics Coordinator**. The Research Ethics Coordinator also encourages researchers to report any unanticipated outcomes of the research process which could be linked to the ethics review process. An active dialogue between the Research Ethics Coordinator and the researcher will ensure that both parties learn as much as possible from each research experience.

Section G – Signatures

The principal investigator must sign a hard copy of the signature page and forward it to the Research Ethics Coordinator to be filed with the electronic submission. The role of principal investigator cannot be filled by a student—a faculty supervisor should take responsibility for the ethical application and subsequent protection of participants. It is important for the principal investigator to carefully review each submission prior to signing since the ultimate responsibility for the contents of the application and the subsequent performance of the project and protection of participants lies with them.

COMMENCING RESEARCH WITHOUT THE PRIOR APPROVAL OF THE RESEARCH ETHICS BOARD IS UNACCEPTABLE AND WILL RESULT IN PENALTIES.